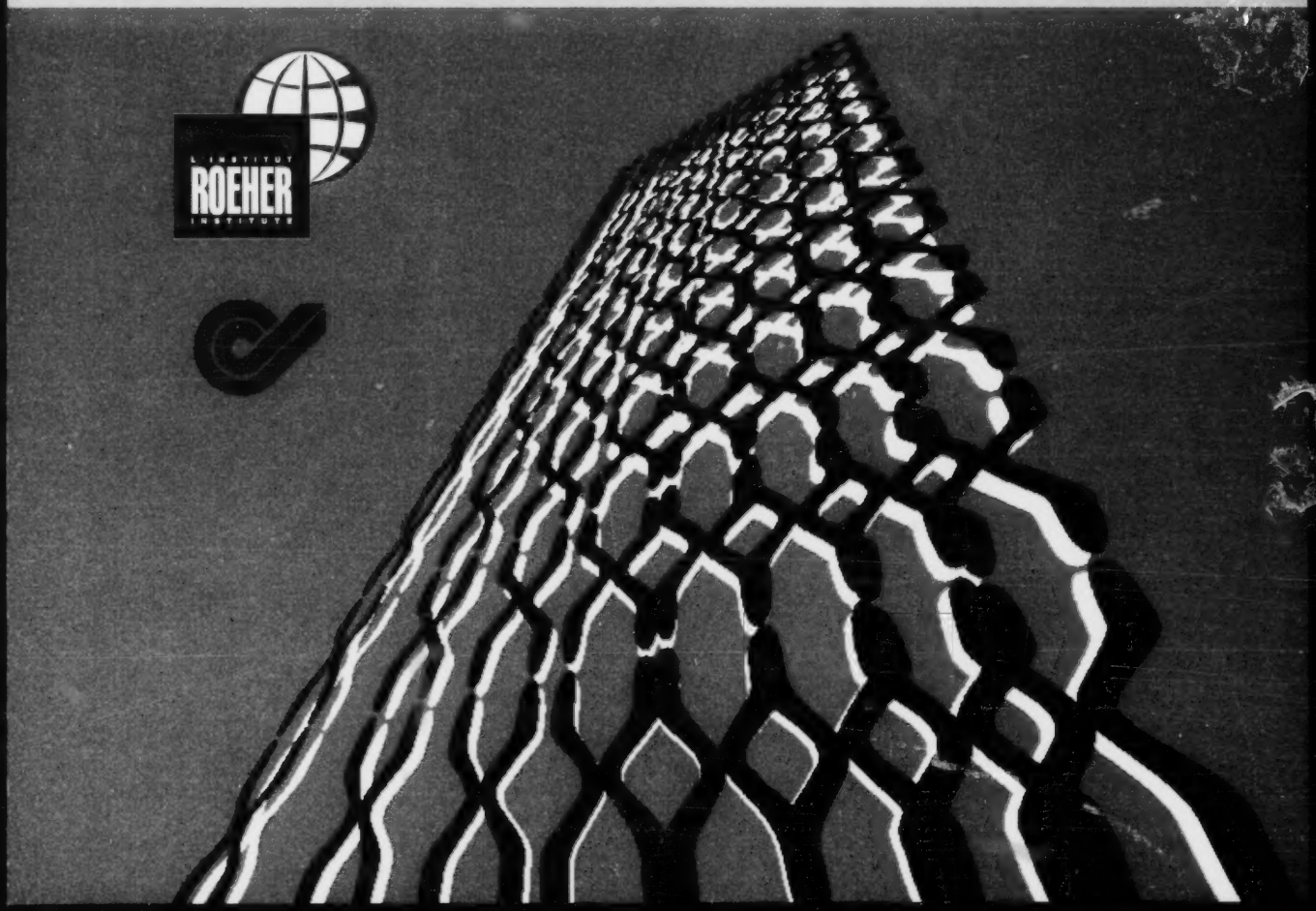
Genome(s) and Justice

Reflections on a Holistic Approach to Genetic Research, Technology and Disability



The Roeher Institute in Co-operation with INCLUSION INTERNATIONAL

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About

L'Institut ROEHER Institute

Canada's National Institute for the Study of Public Policy Affecting Persons with Intellectual and Other Disabilities

L'Institut Roeher Institute is Canada's Policy Research organization promoting the equality, participation and self-determination of people with intellectual and other disabilities, by examining the causes of marginalization and by providing research, information and social development opportunities.

To fulfill this mandate, The Institute is engaged in many activities: research and policy analysis; publishing; information gathering and dissemination; and training, education and leadership development.

The Institute acts as a centre for the development and exchange of ideas, all of which are founded on a new way of looking at disability in the context of a strong civil society. It critically examines issues related to the well-being and human rights of persons with disabilities. Based on its examination of these issues, The Institute raises awareness about the barriers that affect people's full participation in society and that prevent them from exercising their rights. The Institute also presents policy and program alternatives.

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Introduction

In 1995, Inclusion International[1] published a book called *Just Technology? From Principles to Practice in Bioethical Issues.* This publication outlined some potential implications of genetic research and technology for people with disabilities. Inclusion International found that although genetic research can result in treatment and prevention of illness, and in the promotion of health and well-being, it can also undermine the human rights of people with disabilities, endangering their very existence.

In order to ensure that such research and technology is developed and applied in ways that support well-being and protect rights, Inclusion International proposed that genetic research and its applications be evaluated in terms of four principles:

- the principle of justice;
- the principle of non-discrimination;
- the principle of diversity; and
- the principle of autonomy and informed decision-making.

The timing could not have been better. UNESCO had already begun to work on an international human rights instrument called the "Declaration on the Human Genome and Human Rights." From their first draft in 1995 to the adoption of the final document in November 1997, Inclusion International's Open Project Group on Bioethics applied these four principles, evaluating and recommending changes to the UNESCO Declaration.[2] Because of the efforts of Inclusion International, among other groups, the Declaration was considerably improved.

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[1] Inclusion International (formerly International League of Societies for Persons with a Mental Handicap) is a human rights organization advocating with, and on behalf of, people with an intellectual disability.

[2] Inclusion International prepared five documents in response to drafts of the UNESCO Declaration. These are listed in the reference section.

The final document protected human rights much more effectively than did early drafts.

Ways in which an international human-rights instrument can preclude the risks and enhance the benefits of genetic research for people with disabilities were identified throughout Inclusion International's analysis of the UNESCO Declaration. Differences and similarities in the ways that advocacy groups and international organizations such as UNESCO are viewing these issues were clarified.

Inclusion International proposed that genetic research and its application be evaluated according to the following principles:

- The Principle of Justice
- The Principle of Non-Discrimination
- The Principle of Diversity
- The Principle of Autonomy and Informed Decision-Making

*

One result was that Inclusion International gained new solidarity with groups representing the concerns of indigenous peoples. Like people with disabilities, many indigenous peoples perceive that developments in genetic research place them at risk — of harm, discrimination and exploitation. While UNESCO shared some of these concerns, they did not effectively deal with some issues of significant concern to these marginalized groups. Thus, *Genome(s) and Justice* has been developed by The Roeher Institute, in cooperation with Inclusion International, to fill that gap and to serve as a guide to assessing the issues posed by genetics as they relate to people with disabilities. That these issues also apply to other groups should, of course, be borne in mind at all times.

First, it seems appropriate to set out a brief review of the principles recommended in *Just Technology?* This will then be followed by an exploration of issues raised during the process of evaluating drafts of the UNESCO Declaration.

The Principle of Justice

The principle of justice upholds the rights and equality of individuals and groups. It affirms fairness and equality in the allocation of resources: all people have the right to develop their potential and to be provided with what is needed to achieve

individual and social well-being. It rejects economic efficiency and cost effectiveness as ethical principles, and beneficence and best interest[3] as the sole basis of government obligation.

The Principle of Non-Discrimination

The principle of non-discrimination is founded on the belief that everybody has the right to life, to medical treatment, and to acceptance[4] without discrimination based on the existence or expectation of mental or physical disability, or any other characteristic.

The Principle of Diversity

The principle of diversity considers the population in terms of gender, race, religion, functional capacity, sexual orientation, and so on. Diversity implies not a goal of creating better people, but one of making a better world for all of us to live in. Thus diversity rejects technology such as prenatal diagnosis, gene probes, and gene therapy as a means of ridding the world of those who do not meet society's notions of 'normality' or 'perfection.'

The Principle of Autonomy and Informed Decision-Making

Every person has the right to be independent and to make their own decisions. This includes the right, based on free and informed decisions, to receive or refuse medical treatment, health-care measures, research interventions, or knowledge of one's genetic characteristics. It also includes the right to have full information about the risks and benefits of choices, to be told what alternatives and options are available, and to be supported in one's decisions.

These principles were applied to the issues that emerged in the Inclusion International critiques of drafts of the UNESCO Declaration. Passages from the Declaration and from Inclusion International's recommendations will note the ways these four

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3 "Best interest" refers to two notions: that inequality of opportunity and outcome for individuals is acceptable when it benefits the majority; and that a state or authority may legitimately determine what would benefit an individual or group.

4 This is supported by the Universal Declaration of Human Rights (Article 25, 1948); the United Nations Convention on the Rights of the Child (Article 23 & 24, 1989); the United Nations Declaration on the Rights of Disabled Persons (Proclamation 6, 1975); the United Nations Declaration on the Rights of Mentally Retarded Persons (Proclamation 2, 1971); and the United Nations World Program of Action Concerning Disabled People (1982).

principles are, or are not, reflected in various articles of the Declaration. The main issues were:

I. Propensity to reductionism;

II. The importance of human diversity;

III. The threat of eugenics;

IV. Balancing benefits and harms; and

V. Autonomy and participation in decision-making.

1

The Propensity to Reductionism

Physical science is generally thought to be objective: the scientist investigates what is true or false, or learns facts about certain phenomena. Unlike ethicists or social researchers, the work of the physical scientist is not necessarily to make value judgements, i.e., to assess what is 'good' or 'bad' in the facts they find, or to interpret their findings according to their beliefs about the world. However, geneticists and other scientists, like all people, tend to have beliefs and values about the world. Decisions on what to research, and how to use research results take place in a particular social and ideological context. They then influence the way we understand ourselves and our social world.

Societal values and perceived norms direct the thinking that underlies genetics. Social values, in some instances, promote genetic research to benefit people's health and well-being. However, some views of genetics and of people can result in harm to particular individuals and groups. Seeing issues strictly through the lens of genetics can fail to reveal the complexities inherent in these issues.

To the extent that science deals with fact, reductionism is an appropriate methodological tool, since facts are either demonstrably accurate or not. But genetics is not merely facts, it is also value laden.

Concentration on a limited view of reality is called 'reductionism' wherein complexity is either not seen or is stripped away until there remains only one way of approaching an issue. Genetics is more or less a physical science. To the extent that science deals with fact, reductionism is an appropriate methodological tool, since facts are either demonstrably accurate or not. But genetics has to deal with more than facts. It is a value-laden approach to reality and reductionism becomes dangerous when particular aspects of

Finding preventions, cures and treatments for diseases is important, and genetic research will undoubtably contribute greatly to health. However, genetics must be part of an ethical and political context....as genetics is a value-based as well as physical science.

reality are viewed as the most decisive, or the only, aspects of reality. While genetic science and its tool, reductionism, are inherently neither good nor bad, they can be applied in ways that either benefit or harm. The use of reductionism as a means of interpreting findings, rather than merely gathering facts, can harm groups such as people with disabilities. As such, genetics in its reductionist form is an inappropriate (and dangerous) basis for determining health and social policy.

Genetics can result in great benefits, when it is conceived and applied in a manner that recognizes the diverse natural, social and cultural contexts of people, and certainly many geneticists respect this complexity. However, there are risks as both overt and subtle reductionism can underlie the ways we think about health and illness, human diversity, and the purpose of science. For example, finding preventions, cures and treatments for diseases is important, and genetic research will undoubtably contribute greatly to health and well-being. However, genetics must be part of an ethical and political context broader than simple progress in biomedical health if genetics is to contribute to well-being and avoid contributing to disadvantage. As genetics is a value-based as well as a physical science, we must ensure that the values that underlie this research promote and protect human rights. Thus, when principles such as justice, non-discrimination, diversity and autonomy and informed decision-making underlie genetic research and such human rights instruments as the UNESCO Declaration, genetics offers great benefit. Such benefits are also likely when genetics is applied and referred to in a manner that reflects the social and environmental context of health, wellness and illness.

Diverse factors contribute to the health and well-being of both individuals and society. Such factors include among others: a clean

environment, free of pollutants and other hazards; enough money to acquire nutritious food and adequate shelter; a safe home and community, free of domestic or state violence; life in the community including meaningful social relationships; a workplace without risk of occupational accident or disease; access to medical care and treatment; a good education and literacy skills; the freedom to be who you are and to have opportunities and choices; and the right to participate fully in a fair and equitable society. It is widely recognized by organizations such as the World Health Organization[1] that all these factors are necessary to health and well-being.

Yet genetics is being defined simply as a major solution to health problems. Predictions are being made that genetics will cure and prevent illnesses such as cancer and heart disease, and prevent conditions that result in disabilities, such as Down syndrome or Cystic Fibrosis.

Genetic make-up certainly contributes to some illnesses; but it is not, in fact, the only cause of illness or disability. So, there is a danger that if genetics is seen as the sole solution to health problems, attention will be diverted from measures to reduce hunger, malnutrition, environmental hazards, illiteracy and the many other social, economic, and environmental causes of ill health. In terms of disability, the reductionist view of health as primarily a matter of genetics extends and reinforces the traditional simplistic view of disability as a medical issue. Rather than factoring in the social context as a contributor to the difficulties that persons with disabilities face, the reductionist view frames

Diverse factors contribute to health and well-being.... There is a danger that if genetics is seen as the sole solution to health problems, attention will be diverted from measures to reduce hunger, malnutrition, environmental hazards, illiteracy and the many other social, economic, and environmental causes of ill health.

[1] WHO defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" in World Health Organization (1984) Targets for Health for All 2000. Copenhagen: World Health Organization.

disability as an individual medical pathology that needs to be prevented or 'fixed.' Thus, there is a danger that efforts and resources that may otherwise be directed towards removing barriers in society that limit the participation of people with disabilities may be diverted instead towards genetic research.

> It is not the scientists' integrity that is at issue. What we need to ask is whether the underlying framework that guides these activities is a reductionist notion of what is 'normal,' what is 'good' for society, and what is 'good' for people.
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Another form of reductionism that sometimes occurs in relation to genetics is 'geneticization.' The diversity of the human race is demonstrated in ability, ethnicity, gender, sexual orientation, behaviour, attitude, and many other characteristics. The exploration of the human genome[2] seeks to provide genetic maps to explain and measure some of these differences. Some claim that there are even biological or genetic 'causes' of shyness, aggression, morality, sexual orientation, substance abuse, learning disabilities, gender and racial differences. The implicit reasoning is that if there is a genetic blueprint of what makes us who we are, as a species and as individuals, then, by understanding, it we can prevent disease, illness and disability. Further, if we can understand exactly what in our genetic make-up causes different characteristics, we can then 'improve' the species. From this perspective, human difference may be viewed as a mere medical or biological configuration. Therefore, our understanding of who we are is reduced to chromosomal instructions that direct our bodies and personalities to develop in a particular way.

By and large, scientists who conduct genetic research have good intentions in that they are looking for cures and treatments, objectively trying to understand the human body in

[2] in 1989 the international Human Genome Project was launched. It involves a number of countries including Canada, the United States, Japan, France, Britain, Germany, Denmark and Italy. The aim of the project is to determine the sequence of a single full set of human genetic information consisting of around 3000 million nucleotide bases.

order to further human knowledge. The resulting treatments and technologies that they create for medical and pharmaceutical companies are aimed at promoting health and giving people wider choices. However, it is not scientists' integrity that is at issue. What we need to ask is whether the underlying framework that guides these activities is a reductionist notion of what is 'normal,' what is 'beneficial' for society and people.[3] When the framework is reductionist, genetics might be applied in ways that harm, rather than benefit.

Not all scientists go beyond the immediacy of their research to concern themselves with the ethical and social implications or contexts of their research. Many are solely interested in the research per se and may not be motivated by any practical or ideological goal. They are simply interested in mapping and understanding the infrastructure and anatomy of the human genome,[4] as was the case with the lead scientist involved in the cloning of Dolly, the sheep. When asked about the ethical implications of his work, he insisted, "I am only a scientist."[5] As we have seen, however, in the case of genetics, scientific endeavours do not exist in isolation, they take place in a wider social context and their applications sometimes give rise to complex ethical and social dilemmas.

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[3] In early drafts of the UNESCO Declaration, reductionist language repeatedly slipped in, and insufficient attention was given to affirming the importance of social contexts, and of social well-being and human rights. References to the human genome as the "common heritage of humanity" in Article 1, implied that the human genome contains the genesis of the human body. However, the genome alone is not 'being human.' Although the intention of this wording was to safeguard against commercial use of research findings by a few private or state interest groups, it insinuated that the human rights of individuals might be secondary to an assumed benefit to, or the well-being of, humankind. That is the danger for people with disabilities. In the final draft, much of the reductionist language was removed, and there was a significant increase in the recognition of human rights. The human genome is referred to as "the heritage of humanity" but only in a "symbolic sense."

[4] Caplan, Arthur (1992) "If Gene Therapy is the Cure, What is the Disease?" In Annas G. and Elias, S (eds.) Gene Mapping, Oxford University Press, 128–141.

[5] Loka Institute (1998). Genetic Discrimination: A Primer (Interview with Phil Bereano). Loka Alert 5(1), p. 2.*Article 14 (new 17).*

Some terms and definitions:

The Human Genome refers to the total set of genes presumed to be common to human beings only.

Prenatal diagnosis is the testing of live fetuses to determine a genetic disorder. Most commonly used tests are amniocentesis, in which a sample of the fluid surrounding the fetus is extracted by needle and analyzed for fetal cells and metabolites (at midterm), or chorionic villus sampling (CVS), in which a tissue sample of the placenta is taken from the mother's cervix (at 9 or 10 weeks).

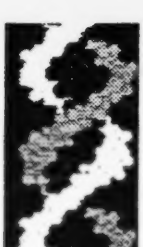
Selective abortion is when the diagnosis of a predisposition to a genetic disorder in the fetus leads to an abortion.

In vitro fertilization involves fertilizing ova with sperm in a test tube. The resulting embryos can then be screened for certain conditions and characteristics. In selective implantation, embryos with "undesirable" genetic traits are discarded, those with "desirable" ones are implanted in the womb.

Germline therapies involve the intentional alteration of the genetic make-up of humans, either prenatally or after birth. Alteration of the genetic material of a person's reproductive cells changes the genetic make-up of future generations, should that person have children.

Withholding treatment is the medical practice of denying access to life-saving treatment to newborn babies with a severe disability; this is usually justified on the expectation of a "poor quality of life."

Sterilization is a medical intervention so that a person cannot reproduce. Sterilization programs have been aimed at preventing certain types of people from having children, generally without their consent.



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The Importance of Human Diversity

Every human being is unique, and there is immeasurable diversity in human characteristics. Some are genetically based, others are linked to culture, environmental influences, or personal choices. Reductionist notions such as geneticization skew our view of diversity, boiling down difference to variations in DNA codes. This perception creates new defining notions of what is 'normal' and which genetic 'defect' or 'mutation' might be manipulated in order to bring an individual's genes in line with 'normality.' This line of reasoning could be extended to include the genetic make-up of whole populations through such interventions as gene therapy, selective abortion and selective implantation. Such actions threaten the human genome itself, and as we gain control over human diversity, new forms of discrimination become possible.

> It is the diversity of the human genome that gives us the resilience and adaptability to stave off extinction....different genetic characteristics allow a species to adapt to new and unpredictable condition...what might be the health impacts of eliminating one of these genes from the human genome?
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Individual uniqueness, human diversity, and variations in the genome are not only natural, they are imperative to human survival.[1] It is the differences between each person and the diversity of the human genome that gives us the resilience and adaptability to stave off extinction. Maintaining maximum diversity is nature's strategy for survival of the species — different genetic characteristics allow a species to adapt to new and unpredictable conditions. We do not have any way of knowing what

[1] Suzuki, David, (1995), "Why We Need an Infusion of Diversity," *The Toronto Star* December 9, 1995, B6.

characteristics, including those associated with disability, may in the future benefit humankind. Furthermore, despite rapidly growing knowledge in this science, we are far from 'understanding' the human genome. Genes are extremely complex and may have more than one function. People with the gene for Cystic Fibrosis, for example, may be less susceptible to typhoid fever, and similarly, carriers of the gene for sickle cell anaemia are less susceptible to malaria. What might be the health impacts of eliminating one of these genes from the human genome? It is clear that now, more than ever, biodiversity is crucial.[2]

> If we believe our genetic make-up defines who we are, our perceptions of what is 'normal' or 'healthy' may be influenced. Already people with disabilities contend with the equation that disability equals illness.
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> ⁜

Human genome analysis itself helps us understand that genetic diversity is characteristic of the human genome. Yet dimensions of this very characteristic may be diminished by human genome analysis and such interventions as germ-line therapies.[3] Germ-line interventions give humans the power to alter the genetic make-up of our species for the rest of human history.[4]

It is important to recognize that characteristics that may be valued at one time, and/or in a particular culture, may be considered disabilities in another time and place. Standards vary

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[2] "The Perfect Baby" *Chatelaine*, August, 1998, 34–43.

[3] In early drafts the UNESCO Declaration failed to protect the diversity of the human genome explicitly. By the final draft UNESCO included appropriate protections of diversity in Articles I and 2b, which state, respectively:

1. The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.

2b. That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.

[4] Because the immediate risks are not solely to the person consenting to the research or medical intervention, germ-line interventions cannot be considered ethical. For both these reasons, such interventions should therefore be prohibited. While some bodies, such as the Council of Europe, have clearly recommended prohibition of germ-line therapy (Recommendation 1100), the UNESCO Declaration makes no such prohibition.

among cultures and over time — all are preferred somewhere — fat or skinny, short or tall, fair skinned or dark skinned. In some cultures, men embody the norm and women are considered a deviation from it. Disability has been viewed variously as a curse and as a blessing, as a punishment and as a means of bringing one closer to God. In the past few centuries, Western society has viewed disability as both a disease of the individual and a disease of the population as a whole. More recently, however, a human-rights perspective sees disability as a social construct and not as a condition requiring rehabilitation.

If we believe our genetic make-up defines who we are, our perceptions of what is 'normal' or 'healthy' may be influenced. Already people with disabilities contend with the equation that disability equals illness. It has taken many years of advocacy and education to have disability recognized as primarily a social and political construct. In this latter view, barriers to participation in the community through the education system and the labour force rather than the individual's physical, neurological, or genetic characteristics are seen as disabling. Whereas the removal of these social and economic barriers improves the well-being of many people with disabilities, geneticization re-enforces the view of disability as illness, for which individuals require treatment.

Deciding which 'mutations' are abnormal or indicative of disease is laden with value judgements. If people suffer, for example, for being short, shy, gay or Black, can gene therapy be seen as the 'cure?'

Deciding which 'mutations' are abnormal or indicative of disease is laden with value judgements.[5] If people suffer, for example, because they are short, shy, gay or Black, can gene therapy be seen as the 'cure?' Which is more likely to be labeled a disease: a

[5] Article 3 of the UNESCO Declaration states: "The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individuals natural and social environment including the individual's states of health, living conditions, nutrition and education." While Inclusion International commended the attention given here to the social and environmental aspects of health and well-being, the use of the terms 'mutations' was found to be to be value-laden. It can be interpreted as expressing negative attitudes regarding human difference. Use of such terms as 'alterations' or 'changes' are more acceptable.

genetic mutation that results in greater than usual physical prowess, or one that results in obesity? What is declared to be 'disease' or 'normal' is highly subjective, and vulnerable to social and political influences. If national and international protections are in place that ensure that those at risk of falling outside the boundaries of 'normal' are included in the process of making these determinations, genetics is more likely to be applied in a way that is truly beneficial.

The seemingly kindly suggestion that it is cruel to bring someone into the world if they are destined (by their genes) to suffer is far more complex than it appears.... Is suffering not being able to walk, or is it living in an environment with steps in front of every door?

Some disabling conditions and illnesses involve physical pain and suffering that cannot be addressed through social measures; biomedical measures that can alleviate or prevent pain are important in such cases. However, the seemingly kindly suggestion that it is cruel to bring someone into the world if they are destined (by their genes) to suffer is far more complex than it appears. How do we determine what suffering fundamentally is and what causes it? In terms of disability, is suffering not being able to walk, or is it living in an environment with steps in front of every door? Far more suffering is inflicted by social ills such as poverty, war and discrimination than by genetic causes. In light of these concerns, does genetic research really represent the most effective or efficient means of diminishing suffering in the world?

Assumptions about what is normal lead to deductions about what is not normal. Yet these very assumptions are pivotal in the history of discrimination and contraventions of human rights. In the past, assumptions of 'normal' have been used to justify both social exclusion and institutionalization of people with disabilities, and to assume rights determined by gender, race, and other differences. Recognition of human diversity is a prerequisite for human rights. That is, rights are fundamental, and cannot be allocated differentially, based on people's characteristics — be that race, gender, or genetic makeup. If a

limited concept of diversity is adopted in instruments designed — as was the UNESCO Declaration — to protect human rights, the inadvertent result might be to contribute to the prevailing injustices that constrain the lives of people with disabilities and other marginalised groups.

Reductionist notions of health and human diversity inform the erroneous (and dangerous) idea that genetics can prevent disability. Such thinking is dangerous because it can divert attention from the social and systemic barriers that people with disabilities face. Disability is most commonly a result of environmental and social conditions such as accidents or malnutrition. People with disabilities will always be present. Yet if selective genetic procedures understand and treat disability as avoidable, not surprisingly, the public's view of people with disabilities is negatively affected. If people with disabilities are perceived as not having a right to exist, which assumption underlies such interventions as selective abortion, discriminatory attitudes may be encouraged towards people with disabilities who *do* live in our societies.

Such attitudes may manifest themselves in a number of ways. Given the increasing availability of prenatal testing, prospective parents who decide not to be tested, or to proceed with the birth of a child who may have a disability, may be blamed for the 'social burden' of a child with a disability. Such parents could be refused health coverage and support if they make this choice. Similarly, late-onset genetic conditions, and propensities for certain illnesses can be predicted before people develop symptoms. Indeed, the range of late-onset diseases that can be predicted is increasing. Employers, insurers, police, educators, and government agencies could use genetic information to deny

If people with disabilities are perceived as not having a right to exist ...discriminatory attitudes may be encouraged towards people with disabilities who *do* live in our societies.

opportunity, to exclude people from work or benefits, to remove health care coverage or to restrict liberty.[6]

It is of great importance that genetics, which is in effect the study of human diversity, be accompanied by the enforcement of protections of diversity.

In light of these concerns, it is of great importance that genetics, which is in effect the study of human diversity, be accompanied by the enforcement of protections of diversity. Care needs to be taken not to restrict the range of normality, nor to exclude people with certain genetic characteristics from being characterized as 'normal.' At the same time, protections need to be in place so that the human rights and social equality of people with disabilities are ensured, and that discrimination based on genetic knowledge is forbidden by law. [7]

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[6] According to the Loka Institute (1998) there have already been examples of these forms of discrimination:

In one instance in the United States a woman with a family history of Cystic Fibrosis refused prenatal diagnosis screening and was notified by the HMO that if she did not agree to be tested and to abort the fetus if it displayed the gene, the HMO would not cover her pregnancy and would not enroll the prospective child. They reversed the decision when she fought it with a publicity and legal campaign.

The American Air Force routinely screened African-Americans for Sickle Cell Trait and refused to allow them to be Air Force Pilots if they had the trait. Sickle Cell Trait is the presence of a single Sickle Cell Gene and does not cause Sickle Cell Anaemia.

[7] Article 6 of the UNESCO Declaration protects against discrimination based on genetic characteristics, stating:

No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

III

The Threat of Eugenics

In 1859, English naturalist Charles Darwin advanced a theory[1] that revolutionized biology. He suggested that because of variations between organisms, some have advantages that allow them to compete better in the struggle for existence. As such, the most 'fit' organisms are likely to produce offspring that inherit these advantageous traits. Darwin called the process 'natural selection.' It is this diversity and capacity for change that enables survival. The same is true of the human genome.

There has been much debate about Darwin's theory, but what is relevant to this discussion is the interpretation of his theories that led to advocating for human interference in this process of selection. Less than 30 years after Darwin's publication, his cousin, Francis Galton, coined the term 'Eugenics' (from the Greek for 'good birth'), referring to the science of improving the human race.[2]

Eugenics Societies and movements sprung up throughout the western world, most notably in Germany, England and the United States. Prominent biologists, social scientists, and social activists embraced the newfound potential to prevent 'racial degeneration' through positive and negative eugenics. Strategies for positive eugenics centred on encouraging the 'fit' and 'well-to-do' to have children. Negative eugenics focused on preventing the 'unfit' from reproducing, through such strategies as institutionalization, prohibitions of marriage and forced sterilization. These programs focused on those considered feeble-minded, insane, criminal or

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[1] Darwin's theories were published in his book, *The Origin of the Species by Means of Natural Selection.*

[2] Galton defined eugenics as "the science of improving the stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognizance of all the influences that tend, in however remote a degree to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had." (Galton, Francis (1883) *Inquiries into Human Faculty*, London: MacMillan, pp. 24–25.)

sexually perverted, as well as those who were poor or belonged to particular racial groups.[3] The movement culminated, but did not end, in Nazi Germany. Nazi eugenic programs resulted in the deaths of millions of Jews, Gypsies, homosexuals, and political dissidents, but began with the killing of the nation's people with disabilities.

Following the war, the extremity and visibility of the Nazi 'racial hygiene' program brought the shocking implications of eugenics to popular attention. The term 'eugenics' rapidly became unpopular. Eugenics societies, renamed 'genetic' societies, shifted their focus from 'improving the stock' to genetic research, education and practice. In many countries, however, eugenic laws that enforced sterilization and institutionalization of those considered unfit to reproduce, or that restricted immigration of particular racial groups or types, remained in place. (Eugenic sterilization laws directed at people with disabilities and First Nations people, for example, were applied in Canada into the 1970s and are still on the books of about 20 American States.)[4] Around the world eugenics is thriving; laws, policies and social pressures reflect both positive and negative eugenics. Genetic interventions, such as gene therapy 'enhancement' and reproductive technologies for 'disease prevention,' or 'reproductive choice,' introduce both new ways to act on eugenic values and a euphemistic language in which to talk about it. The use of these technologies to prevent the existence, and thereby rid the world, of people with disabilities or with other particular characteristics is referred to as 'selection by prevention.' This

Strategies for positive eugenics centred on encouraging the 'fit' and 'well-to-do' to have children. Negative eugenics focused on preventing the 'unfit' from reproducing, through such strategies as institutionalization, prohibitions of marriage and forced sterilization.

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[3] Hubbard, Ruth (1997). "Abortion and Disability: Who Should and Should Not Inhabit the World?" Lennard J. Davis (ed.) *The Disability Studies Reader*, New York: Routledge, 187–202.

[4] Ibid. 187–202.

modern form of eugenics, which focuses on trying to prevent the birth of 'imperfect' human beings, is based on assumptions that people not seen to be productive or attractive, and/or perceived to be threatening, burdensome or diseased need not exist.

It is important to point out that not all measures that aim to prevent disabilities are based on eugenic values. Many countries have policies and programs that focus on preventive measures that address environmental risks or malnutrition, or that provide supports or biomedical treatments for people who have disabilities or are ill. Such preventive methods that focus on making the lives of people better, not on creating better people, do not pose risks to people with disabilities.

Not all measures that aim to prevent disabilities are based on eugenic values ... preventive methods that focus on making the lives of people better, not on creating better people, do not pose risks to people with disabilities.

Eugenic values are not necessarily enforced by law. Social and economic pressures also exist for selective abortion, based on the detection of a disabling condition. In a recent Canadian survey 30 to 53 percent of genetic counsellors or doctors polled said they would emphasize the negative when counselling patients, if they knew the fetus was going to develop a medical or genetically linked disorder that would lead to profound mental retardation or an early death, in order to encourage their client to seek an abortion.[5] The same pressures urge the use of all available tests, as doctors can be sued for not informing prospective parents of each new development. Further, parents are considered irresponsible for choosing to bear children who will be a 'burden to society.' In fact, there have been cases in a number of countries where 'wrongful life' and 'wrongful birth' suits have been brought against parents or doctors in the event of the birth of a child with a disability.

Eugenic approaches to health involve a number of basic concepts. One is that of 'population health.' The mass exterminations by the Nazis were seen as sanitary, rather than punitive

[5] *The Toronto Star*, "Eugenics Revival Possible: Scientist." December 31, 1995, A 17.

Many measures offered by genetic research eliminate disability by eliminating the potential person with the disability. Even less radical measures, such as gene therapy, change the nature of the human genome, lessening diversity forever.

measures; their aim was to 'cure' the collective of threats to its health.[6] Contemporary discussions of genetics also refer to potential improvements of the health not only of individuals, but of the human race as a whole.[7] But how does one define the health of the entire human race? And if genetic research offers the cure, what is the disease? Ultimately it must come down to the argument that it is better for humankind to be without certain categories of people. This, of course, denies the collective right of people placed in those categories to be part of the human family.

The second element of eugenic logic is the idea that we can, and should, 'perfect' the human race. This goal would be achieved through 'selection by prevention' — the application of technologies such as sterilization, selective abortion, selective implantation and withholding treatment to ensure that fetuses with identifiable genetic conditions either are not born or do not survive after birth. Underlying such actions is the assumption that certain genetic conditions, often associated with disabilities, represent genetic defects, constitute pathologies, and ought to be prevented. (Of course, this perspective fails to recognize the extent to which disabilities result from a society that does not provide the supports people require because of their differences and conditions.)

These two basic concepts — the elimination of disability for purposes of population health, and perfecting the human race — are commonly perceived to be universally beneficial. However, the

6 See Hubbard (1997).

7 Article 12b of the UNESCO Declaration states that " The applications of [genetic] research, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole." Inclusion International suggested the removal of reference to the "health of human kind as a whole" and the addition of the following human rights protection and concern for well-being:

> Research must be governed, conducted, validated and applied in a manner that is consistent with the principles of human rights. Research and its applications, especially in biology and genetics, should promote the health and well-being of all persons.

characteristics of eugenics are culturally specific, the result of pre-existing social inequalities. Identifying and eliminating an undesirable genetic characteristic could be deemed of value only if persons with that particular characteristic are seen to be undesirable. It is, therefore, dangerous to presume that people with different abilities do not have value. Moreover, achieving these aims is not a simple matter of tweaking a gene and making a person's disabling condition go away. While there are a few genetically based treatments that provide such uncomplicated benefit, many measures offered by genetic research eliminate disability by eliminating the potential person with the disability. Even less directly radical measures, such as germ-line therapy, change the nature of the human genome, lessening diversity forever.

When human rights and a respect for human diversity are the values underlying genetic research and its applications, genetics can produce interventions that improve health and well-being, and create choices.

When human rights and a respect for human diversity are the values underlying genetic research and its applications, genetics can produce interventions that improve health and well-being, and create choices for prospective parents and people with genetic conditions or propensities to particular illnesses. With eugenic values underlying the measures, there is an intent or pressure, whether implicit or explicit, to prevent the birth of certain categories of people.

Genetic technologies to improve the health of populations or to perfect human beings are eugenic in nature. Therefore, prohibitions against eugenics need to be explicit to ensure that genetics contributes to health and well-being. Unfortunately, eugenic values cast a pall on exciting 'good' potentialities of genetics. Ironically, people tend to accept eugenic practices, as long as the term 'eugenics' itself is avoided. For example, the UNESCO Declaration makes no effort to put in place protections prohibiting eugenics, which can only be interpreted as an implicit sanctioning of these practices. This underscores the urgent need to

prohibit eugenics[8] and, at the very least, to put in place protections to ensure that human rights, diversity and social well-being will be considered in conjunction with health.

[8] A reference to the prohibition of Eugenics did exist in an early draft of the UNESCO Declaration. However, it was deleted from the final drafts. No reference to Eugenics currently exists in the document, despite Inclusion International's repeated emphasis on the importance of this protection. By omitting any reference to eugenics, the Article not only fails to prohibit eugenics, it also implicitly sanctions such practices. Inclusion International recommended that protections against eugenics be incorporated in the UNESCO Declaration in Article 17 as follows:

> States must ensure that *researchers and other citizens* fulfill their duty of solidarity to, *and promote the well-being of,* individuals, families or population groups who are particularly vulnerable to disease or disability due to their genetic characteristics. *States must strongly reject all eugenic programs as discriminatory and against the personal and common genetic heritage. They must affirm that bio-diversity is not only desirable but is the optimum strategy for survival and, therefore, must be protected.*

Some contemporary eugenic laws, policies and practices:

Singapore instituted numerous eugenic policies, including the provision of financial incentive for 'smart' people to have more children in the 1980s.

Sperm banks, such as the California-based Repository for Germinal Choice (known as the Nobel Prize sperm bank), that seek out and store the sperm of men who excel in science, athletics, or business are emerging.

In several countries, pregnant women over the age of 35 are routinely advised to undergo prenatal diagnosis, abortion being recommended if a disability is detected.

Discovery of the gene for Cystic Fibrosis led some scientists to advocate for "mass population screenings" for the gene with the aim to ensure a more informed reproductive decision, and substantial cost-savings in disease care and management.

In the United States, it is estimated that 2.7 million carrier tests will be conducted each year for Cystic Fibrosis, Sickle Cell Anemia, and Duchenne muscular dystrophy; 2.4 million to detect chromosomal abnormalities; 16.2 million each year to identify individuals at risk to common diseases such as breast cancer and Alzheimer (Sharpe, 1997).

In China, the Law on Maternal and Infant Health Care, enacted in 1995, stipulates that persons with "genetic diseases of a serious nature" be sterilized before marriage is permitted.

In California, the law requires that pregnant women be standardly offered a test to detect neural tube defects. Women must sign a consent or refusal form to take the test. Women must refuse it actively, they cannot just ignore it (Hubbard, 1997).

IV

Balancing Benefits and Harms

Developments in science contain within them the potential for both benefit and harm. Such developments can improve or detract from health and well-being. They can enable or restrict social justice and the autonomy, equality and self-determination of individuals and groups. It seems simple to say that we should therefore ensure that science is used in ways that benefit, and that may be the intention of geneticists and others who are applying such developments. Yet determining what is beneficial is very complex. Consensus does not exist among geneticists, ethicists, advocacy organizations or human rights organizations regarding which genetic applications are 'good' and which are 'bad.' Dilemmas arise because certain applications that might benefit some parties could harm others. For example, who benefits and who is harmed by which applications of knowledge? How do we negotiate situations where the rights of one group seem to conflict with the rights of another? How do we ensure that science is informed and directed by a respect for human diversity, social equality and human rights?

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Scientific research provides obvious benefits when it increases our understanding of social and physical phenomena, and provides us with the tools to do things we could not do previously, or enables us to do things more efficiently. Although it is a relatively new field, the last hundred years have seen many exciting developments in genetic science. Genetics offers insights into details of the biological aspect of living and of reproducing life.

People have access to information they never had before about human bodies in general, and their own bodies specifically. Amazing cures or treatments for cancer, AIDS, heart disease and many other illnesses may one day be possible through genetics. Because of this potential, genetic research is sometimes treated as inherently beneficial to human well-being and to individual classes of persons. Notwithstanding the potential to provide benefits, it would be unwise to assume benefits are inherent to genetics. As we have seen, genetics is just as likely to compromise as to advance well-being if its application is based on reductionist and eugenic approaches to health, human diversity and disability.

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Despite the beneficial objectives of scientific research it is important to evaluate scientific developments and their applications and guard against their potential harms. As we have seen, applications of genetics that are based on eugenic values or that threaten human diversity may be extremely harmful. Moreover, in some cases, even when the objective has been to promote health and well-being, research has contributed directly or indirectly to the marginalization of people with disabilities and/or the exploitation of indigenous populations. For example, Depo Provera, a birth control injection for women, is intended to increase their own control over reproduction. However, it has been used to control the reproductive capacity of women with disabilities, aboriginal women and women in developing countries, without their informed consent. Possible side effects include, among others, depression, headaches, loss of sex drive, infertility and risk of cancer.[1] In terms of indigenous populations, some genetic cures and treatments are the result of what has been termed 'biopiracy.' This is when scientists and drug companies collect and commercialize genetic material from indigenous populations, as in the case of one genomics company's plan to patent an asthma gene found among the people of Tristan

[1] Disabled Women's Network. (date unknown) *Depo Provera: From Stories to Struggle: Women Creating Reproductive Freedom.* Ottawa: Women's Health Interaction.

da Cunha (near Brazil), a group who would themselves see none of the profit.[2]

It is important also to recognize that benefits accrue to different parties. When used to reduce hunger, research results may promote the health and well-being of the world population. The invention of a particular drug or therapy may benefit the health and well-being of people with particular illnesses or diseases. Its discovery may result in financial and professional rewards to the inventors and its marketing may offer commercial advantage to particular medical or pharmaceutical companies. Financial benefits may also accrue to states that are enabled to save money on health and social programs.

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However, benefits are not a simple thing. What benefits one party can harm another. Thus difficult decisions are made about what constitutes the greatest good, and for whom. Ethical dilemmas arise as the consequences of an application of research are weighed. In the case of prenatal screening, for example, termination of pregnancy when a disability is detected may be expected to save money for families, health care service providers and states,[3] but what are the social and ethical costs?[4] Such an analysis presumes that economic efficiency is of more value than

[2] *The Body Mind and Spirit Directory* (1995) "Is Nothing Sacred? Gathering Human Genetic Samples Raises Many Questions." The Utne Lens, http://www.utne.com.

[3] A cost-benefit analysis is often used to evaluate new genetic technologies. For example, cost-benefit analyses of prenatal-screening services may have termination of pregnancy as the program objective. Screening programs are only cost-effective if financial costs of tests are balanced by the savings from avoiding the birth of affected children. (Mykitiuk, Roxanne and Penny, Steven (1995) "Screening for Deficits: Legal and Ethical Implications of Genetic Screening and Testing to Reduce Health Care Budgets." *The Health Law Journal*, Vol. 3 235–268.

[4] While Article 4 of the UNESCO Declaration requires that "The human genome in its natural state shall not give rise to financial gains," more explicit protections are needed to ensure that scientific, professional, commercial or other interests shall never prevail over the obligation to promote the well-being of all individuals in society.

diversity, equality and justice. In this view the lives of 'affected children,' that is, children with disabilities, are assumed to be not only without value, but to represent a burden on society. It is vital that measures to make these determinations consider not merely cost-effectiveness, but also social impacts, considering the dangers when any other interest prevails over the human rights and well-being of individuals or groups. [5]

It is vital that measures to make these determinations consider not merely cost-effectiveness, but also social impacts, considering the dangers when any other interest prevails over the human rights and well-being of individuals or groups.

Genetics offers new possibilities and introduces new kinds of ethical dilemmas, many of which are highly sensitive, controversial or politically charged. There are not necessarily simple answers to questions of organ cloning and animal organ transplant in humans. Evaluating the positive and negative impacts of research and its applications can be a balancing act when the benefits to or rights of some groups seem to conflict with those of another group. In balancing the rights of various groups, it is not always clear what is right, just or appropriate. How do we approach the dilemma posed in promoting the rights of one group when such rights appear to come at the expense of another group? This is a difficult ethical question in light of the potential harms to any group or individual when their rights are suppressed. Arguments for the rights of people with disabilities with respect to genetics have been countered with arguments for benefits to society as a whole and to future generations, women's rights to reproductive choice, and rights to cultural determination.

[5] In Article 19a the UNESCO Declaration requires the assessment of risks and benefits and prevention of abuses, with reference to inequities between developing and developed countries. Inclusion International is pleased with these protections, but suggests they could be stronger if they included evaluations by social-risk analysis, which acknowledges the social and financial inequities and risks posed to people with disabilities as well as those in developing countries. As it stands, the Article suggests that States should seek to encourage measures that assess the risks and benefits of research on the human genome, and that these measures be carried out to prevent abuse.

It important to provide benefits for, and to protect the rights of, all of these groups. In any society that discriminates against particular groups, it is wise to examine the assumptions and values driving scientific research to see whether, and/or how it might have an impact on these groups. It is equally important to assess the influence that scientific research itself can exert on the society's prevailing attitudes towards these groups. The ongoing debate about genetics, ethics and human rights will not be easily resolved with so many interests at stake. However, maximum benefit and minimum risk can be ensured if such determinations are based on a human rights perspective.

In any society that discriminates against particular groups, it is wise to examine the assumptions and values driving scientific research to see whether, and/or how it might have an impact on these groups.

Such a perspective would not justify the lessening of individual rights in order to benefit society. Historically, such abrogations have tended to affect the same classes of people who are vulnerable to harm from genetics. A human rights perspective requires that in a just society, no group's rights are suppressed. Yet, such an exception has been proposed with regard to genome research for which human subjects are needed. In cases where individuals are deemed to lack the capacity to consent or to communicate decisions concerning treatment,[6] there has been some concern that genetic screening or research may be conducted in favour of 'overriding interests.'

[6] In Article 5e of the UNESCO Declaration, human experimentation without consent is raised and condoned in relation to research, treatment and diagnosis of a person. There is no justifiable legal and social basis for the special exemption being proposed. It is arguably based on a discriminatory presumption for which there is no justification if there is no arguable therapeutic benefit to the individual, but only a benefit to others. The Article states:

> If according to the law, a person does not have that capacity to consent, research affecting his or her genome may only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law. Research which does not have an expected direct health benefit may only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and if the research is intended to contribute to the health benefit of other persons in the same age category or with the same genetic condition, subject to the conditions prescribed by law, and provided such research is compatible with the protection of the individual's human rights.

The notion of 'solidarity' with future generations raises the complex issue of balancing the rights of individuals today with the rights of generations to come. When based on a human rights perspective, solidarity may mean implementing such long-term measures as the elimination of poverty, pollution and war, to ensure that the following generations will inherit a world where they live freely and equitably and their health and well-being is promoted. Genetic research, it has been argued (in particular the aim to eliminate disease and disability), is, in part, a solidarity with future generations. As such, the health of future generations has been used to justify exceptions from the right to consent to participate in research, as well as the practice of eugenic policies and programs.

However, measures to change the human genome involve more complex ethical issues than measures to eliminate poverty, even aside from the problems inherent in reducing genetic diversity, or eugenic notions of 'perfecting' human beings. How do we balance the rights of people with disabilities today against the right of future populations to have no disabilities? In the light of our willingness to pollute the environment — which will have a detrimental effect on future generations — is it plausible that we are motivated by the benefit to future generations in removing rights so that genetic research or interventions can take place? Could not the removal of rights simply be a pretext for present-day interests in the research community or the pharma-industry? Moreover, is making decisions in the interest of future generations a fair burden for individuals as they make reproductive choices, or choices to participate in research?

Arguments have also been made that an individual's rights to refuse genetic testing may be overridden if the purpose of the research is to prevent or repress crime.[7] There are two problems, however, with this approach. First, in many countries, people of

[7] Former drafts of the UNESCO Declaration permitted exceptions to individual rights in cases where the purported purpose of a genetic research project or application is to prevent or repress crime. The final draft had improved protections significantly in this area by removing specific reference to crime, and ensuring that protections of international law and human rights regulate any limitations on the principles of consent and confidentiality. Article 9 reads:

> In order to protect human rights and fundamental freedoms, limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights.

colour, aboriginal people and people with disabilities are disproportionately represented in the penal system because of existing social inequities. In light of this, not only does such research profit because of existing inequity, research results would be skewed as a result of bias in the selection of research subjects. Second, exempting individual rights to consent to genetic research, treatment and diagnosis in order to prevent or repress crime is useful for a very small proportion of offences. Offences, such as the abuse of people with disabilities, women and children, are underreported, tend to be poorly investigated and are rarely prosecuted. The offender, in the vast majority of such cases, is known to the victim. Thus, the offender's identity, which could be established through genetic testing, is rarely at issue and genetic testing would serve no purpose. Instead, exemptions to individual rights should be allowed only when they can be demonstrably justified in a free and equitable society. Many, but not all, measures to protect public safety will meet this test.

It is essential that we avoid categorically based discrimination by protecting collective rights based on ethnicity, gender and genetic characteristics, and the collective rights of indigenous peoples, as well as individual rights.

Another example of apparent rights in conflict is the right to cultural self-determination and the right of people with disabilities to equality and non-discrimination. It has been argued that respect for and tolerance of cultural differences include a recognition that there is no common moral authority among cultures. Respect for cultural difference is extremely important, but cannot exist at the expense of human rights. There is a distinction between individual rights to making culturally based decisions and the use of culture as a rationalization for state policies and programs that contravene human rights. For example, culturally based rationalizations and attempts to control population growth do not justify the overt eugenic practices of certain states.[8] Nor can human rights

[8] See a review of contemporary eugenic practices on pp. 20–22.

protections be subject to legal differences among states.[9] Were exceptions to individual and collective rights to be made based on state differences in culture, law and policy, marginalization and devaluing of groups, as is common worldwide in the case of disability, would be further entrenched. It is therefore essential that we avoid categorically based discrimination by protecting collective rights based on race and ethnicity, gender and genetic characteristics, and the collective rights of indigenous peoples, as well as individual rights.

9 Previous versions of Article 8 suggested that the rights of citizens to be compensated for harm depended on state law. This is somewhat improved by the inclusion of a reference to international law, holding states more broadly accountable. But Inclusion International asserts that it is the duty of governments to anticipate and respond to any negative impacts of scientific, economic and other developments, and recommended the removal of reference to "under conditions of the law." Article 8 states:

> Every individual shall have the right, according to international and national law, to just reparation for any damage sustained as a direct and determining result of an intervention affecting his or her genome.

V

Autonomy and Participation in Decision-Making

Genetic research and their resulting technologies raise further complex questions at the levels of public policy and individual decision-making. With respect to individuals, what new choices requiring decisions have emerged in the context of new information and health and reproductive interventions? What rights and social conditions influence the new decisions individuals are required to make? More broadly, the direction and application of scientific research depend on the political and ideological bent of governments, corporations, the public and the scientific community. Thus, social policy decisions regarding genetic research are influenced by scientific curiosity, social attitudes about health and disability, and economic considerations. At every stage the questions must be asked: Who is making these decisions and on what basis? Whose interests do they serve?

Individuals are faced with decisions that carry their own potential to benefit or burden. For example, the availability of tests for genetic information opens up both new choices and new potential outcomes for individuals.

Even with international protections, individuals are faced with decisions that carry their own potential to benefit or burden. For example, the availability of tests for genetic information opens up both new choices and new potential outcomes for individuals. Although access to testing varies among nations and classes, where tests are available and accessible, prospective parents may now make previously impossible decisions about pregnancy. The parents' first decision may be to choose whether to undergo tests that will determine if a fetus has a disability. (While testing can detect the presence of a

disabling condition, it is not able to determine the severity of the disability, nor, in some cases, at what point in the potential child's life it will appear.) Similar decisions now must be made by individuals who have a family history of late onset diseases, such as Huntington's disease, for which there is a predictive test but no cure. They must decide whether to be tested, whether to encourage relatives to be tested, and whether to test their future child prenatally. Such knowledge could be a benefit by informing an individual's life choices and providing opportunities to reduce health risks and/or prepare for the onset of a disabling condition or illness. However, the knowledge itself may be a burden as it causes anxiety, creates new difficult choices, and introduces new criteria by which individuals might be blamed for illness or disability.

Yet, people are not always given real choices with full information about the technologies and treatments available. They are therefore not always in a position to make a free and informed decision to access or refuse medical treatment, health-care measures, reproductive interventions, research interventions or knowledge about their genetic characteristics. As well, there are varying social, legal and/or financial pressures on women and families around the world to terminate pregnancies or withhold treatment from newborns with disabilities.

People are not always given real choices with full information about the technologies and treatments available. They are therefore not always in a position to make a free and informed decision.

In recognition of the importance to provide full information without directing individuals' choices, genetic counselling is recommended and, in some cases, required to ensure informed consent for genetic testing.[1] Despite this

[1] According to the The Royal College of Physicians and Surgeons of Canada, physicians are required to have the ability "to communicate at a level appropriate to the consultant or the referring physician implications concerning the medical implications and prognosis, the risks that apply, the options available, and to help the individual/family choose an appropriate course of action for themselves, and be able to advise them regarding support agencies." The Royal College of Physicians and Surgeons of Canada, (1994). *Specialty Training Requirements in Medical Genetics*. Ottawa: The Royal College of Physicians and Surgeons of Canada.

requirement, there are as yet no generally accepted standards for genetic screening or genetic counselling. In addition, very few studies have been done with respect to informed consent protocols for genetic conditions other than Cystic Fibrosis and Huntington's disease. Given the growing demand for testing and the shortage of qualified geneticists and genetic counsellors, it is likely that genetic counselling will continue to be provided by primary physicians. Consider the implications of this in light of one recent study that found 40 percent of referring physicians believed that physicians, rather than patients, should decide which fetal anomalies justify abortion.[2]

Even when health professionals are truly non-directive, proceeding with the birth of a fetus with a disability is not always a viable choice. As Ruth Hubbard has pointed out, some women today are in a position where they may seem responsible for what a disability will mean for their child, their family and their society if they choose not to take a prenatal test, or not to terminate a pregnancy when a disability is detected in the fetus. These women risk reproach from others for having 'caused' both the physical pain that might be associated with a disabling condition, and the potential 'social pain' experienced by a person with a disability in a society that discriminates against them.[3]

As we have seen, health-care agencies have attempted to deny coverage to women refusing abortions, and 'wrongful life' and 'wrongful birth' suits have been brought against parents by children, or against doctors by parents when a choice to detect and 'prevent' disability was not made. Furthermore, the lack of supports and services for people with disabilities and their families make it difficult for women and families to exercise true choice and self-determination.

These issues are further complicated by the fact that there is not yet a concensus within and between societies that either the right to reproductive choice for women or the right of people with disabilities to exist are fundamental rights. Because of this, and the seeming opposition between the two rights, the debate in this area has been an extremely difficult and sensitive one. If we view both

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2 Michie et al., cited in Sharpe, Neil (1997). "Reinventing The Wheel?: Informed Consent and Genetic Testing For Breast Cancer, Cystic Fibrosis, And Huntington Disease. *Queen's Law Journal*, 22(2) Spring, 389–452.

3 See Hubbard (1997).

> The lack of supports and services for people with disabilities and their families make it difficult for women and families to exercise true choice and self-determination. Women and families need...assurance that they will receive support if they choose to proceed with the birth of a child with a disability.
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rights as fundamental, we are posed with the following dilemma: Choosing to abort fetuses with a disability, on the basis of that disability, is ethically unacceptable because it discriminates and devalues the lives, worth and unique qualities of people with disabilities, and supposes that we have the right to choose the qualities of people being born. Yet, refusing women the right to choose an abortion denies her right to control her body and her choices about reproduction. As difficult as these determinations may be, in light of the pressures on women to undergo genetic testing and abort fetuses diagnosed as having a disability, there are four measures that may begin to address the issue of protecting the collective rights of persons with disabilities without compromising women's right to choose. First, states can avoid, or make illegal, widespread programs aimed at explicitly pressuring or implicitly directing women to undergo testing or abortion on the basis of disability. Second, they can also provide assurance through legislation and human rights provisions that those who refuse genetic intervention or who do not share genetic information about themselves or others will be protected from discrimination. Third, inclusive policies can be developed that ensure supports for persons with disabilities and their families are available that would assure them equal socio-economic opportunity and full citizenship, allowing them real options. Finally, activists, ethicists, genetic counsellors and governments can make efforts to educate and inform prospective parents and others about the positive aspect of the lives of persons with disabilities, and of living with a child with a disability.

It should also be noted that access to reproductive technologies (and to other medical options such as organ transplants) are not always equally available to people with

disabilities and other marginalized groups. Since these technologies are expensive, a decision has to be made whether it is justified to withhold fertility technology from those who do not meet society's standards of 'normal' or are likely to rear children who may not meet these standards. The associated risk is that only people enjoying a privileged status in society will have access to selective technologies, especially in developing countries. A result may be that people who are poor are more likely to have children with disabilities. Since people with disabilities often experience societal barriers to equal economic opportunity, this could widen the gap in economic differences between classes and countries, and further entrench poverty in the population that has a preponderance of disabilities.

Another decision-making issue arises out of existing limitations of the right of people with disabilities to decide whether to undergo medical intervention. In most countries, paternalistic decision-making mechanisms based on the principle of 'best interest' assume that certain persons cannot make decisions about their health and well-being, even with support. This paternalism has had deleterious consequences for people with disabilities, including institutionalization, non-therapeutic sterilization and withholding medical treatment. With genetic interventions, experimental or otherwise, decisions might be made that would be of greater harm than benefit not only to individuals but also to their descendants. It is important to recognize that the presumption of incapacity has been systematically and commonly imposed. In some countries, alternatives to paternalistic decision-making are being used: people previously labelled as lacking the capacity to decide are being supported so that they can make decisions in an atmosphere of respect for human rights, dignity and freedom.

It has been suggested that people seen as lacking the capacity for consent may be made participants in genetic experimentations for their own best interest or the overriding interest of society, based on substitute or third-party consent.[4] Such actions would open the door to misusing society's most vulnerable, marginalized and devalued people. It could be viewed as a human rights abuse,

[4] These concerns were raised by the delegates of the 14th World Congress of Society Psychiatry, with reference to the Bioethics Convention drafted by the Council of Europe.

because of possible impacts both on the participants and on future generations, from whom, obviously, there is no way to obtain consent. For these reasons, free and informed consent to participate in genetic experimentation must be duly obtained.[5]

Related to issues of consent are issues of confidentiality, because confidential information about people's genetic make-up has been used by researchers, employers or insurance companies without their knowledge.[6] It is therefore essential that confidentiality of genetic information be protected and subject only to the rights and freedoms of the individual to whom it pertains. Laws and interpretations of social benefit (i.e., the 'general interest') to be achieved by disclosing such information must be subject to the closest scrutiny.[7]

Proponents of genetic research recognize that there are ethical concerns and social risks associated with genetic research. Ethics committees and conventions are formed at project, state and international levels to review some of the social risks and benefits of genetics. The efforts and contributions made by such committees are to be commended; however, questions remain. For example, who are the members of these committees? What values

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[5] Article 5b fails to uphold the rights of people whose capacity to consent could be called into question. People who are not in a position to consent or dissent without support can still be assumed to have the capacity to designate whom they would like to participate in the decision-making process. Inclusion International recommended that this subsection acknowledge capacity to consent with support, and require that the wishes of such individuals be conveyed by duly authorized representatives, and that the decision-making processes involving individuals and their representatives will respect human rights, dignity and freedom. Article 5b reads:

> In all cases, the prior, free and informed consent of the person concerned shall be obtained. If the latter is not in a position to consent, consent or authorization shall be obtained in the manner prescribed by law, guided by the person's best interest.

6 There have been recent cases where genetic information has been obtained without people's consent (The Loka Institute, 1998):

- An insurance company in Massachusetts has a database with 15–20 million personal records on it, which most people do not know about.
- The director of the National Institute of Health's (US) ethical program for the Human Genome Project was able to access blood taken for Tay Sachs disease 20 years earlier without donors' permission or knowledge to test for a cancer gene.
- A laboratory in California has been testing women, African-American and Hispanic employees for pregnancy, Sickle Cell, and Hypertension without their knowledge or consent.

[7] The UNESCO Declaration does protect confidentiality in Article 7. However, Inclusion International recommended a stronger protection that would require that genetic information

and intentions underlie their thinking and decision-making?[8] For the most part, genetic scientists and doctors, and the governments and industries funding them, decide the direction, and thereby the ethics underlying their research. Their intentions are to benefit people and societies, and many have made positive contributions, including improvements to health and well-being for people with disabilities. It must be borne in mind, however, that they are influenced by their societal and cultural assumptions about difference and disability. Many are not well informed about the social and political issues surrounding disability, nor are they necessarily aware of societal supports that can enhance well-being for people with disabilities. Just as scientists are expert in their areas of research, so people with disabilities and their advocates are expert in disability issues. Were they to have a voice in decisions about genetic research, the results would be more likely to positively affect their lives.[9]

For the most part, genetic scientists and doctors, and the governments and industries funding them, decide the direction, and thereby the ethics underlying their research.

Political and economic forces influence genetic research and its application. Those with economic power can pressure or influence how genetics will be applied. Governments, hospitals, insurance companies and employers have concerns about the cost of

about individuals not be shared with third parties except at the express wish of the person whose genetic data is involved. The article states:

> Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law.

[8] The International Bioethics Committee (IBC) is a self-appointed body by UNESCO to draft the Declaration on the Human Genome and Human Rights. It does not include representatives of categories of people who have been disenfranchised, including people with disabilities, aboriginal people, the elderly and others, as was suggested by Inclusion International.

[9] Article 21 requires that:
States should take appropriate measures to encourage other forms of research, training and information dissemination conducive to raising the awareness of society and all of its members of their responsibilities regarding the fundamental issues relating to the defence of human dignity which may be raised by research in biology, in genetics and in medicine and

treatment and services for people with disabilities. The prevention of disability through such techniques as genetic screening and selective abortion is sometimes proposed as a simple, cost-effective solution. In such decision-making, cost-effectiveness should never take precedence over the value of life and human rights.

Research and technologies, once developed, can be used in a harmful or beneficial way depending on who is using them. Measures need to be in place to ensure that no one group, society or perspective dominates the ethical evaluation and human rights protections with respect to genetics,[10] for these decisions could have an impact not only on the lives and rights of people in this generation, but of all generations to follow. Therefore, the participation of affected populations in decision-making must be ensured.[11]

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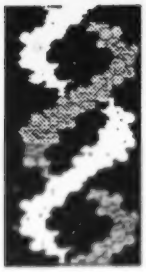
its applications. They should also undertake to facilitate on this subject an open international discussion, ensuring the free expression of various socio-cultural, religious and philosophical opinions.

Inclusion International agrees, but feels strongly that there must be requirements that measures take into account the express views of those who have been (or represent those who have been) disenfranchised by eugenic policies and practices based on characteristics such as national or ethnic origin, colour, gender, age, religious creed, or mental or physical disability.

[10] Inclusion International supports the requirement of states to establish ethics committees, but adds that they should include a focus on eliminating the risks identified. They should also include, among other perspectives, the participation of groups at particular risk from genetics, such as people with disabilities. Article 16 of the UNESCO Declaration states:

> States must recognize the importance of promoting, at various levels, as appropriate, the establishment of independent, multidisciplinary and pluralist ethics committees to assess the ethical, legal, and social issues raised by research on the human genome and its applications.

[11] Inclusion International strongly recommended that a monitoring mechanism and process that safeguard the interests of those most vulnerable groups be put in place. Clearly, this UNESCO Declaration has an impact on a broad variety of interests such as United Nations agencies, nation states, vulnerable groups, indigenous peoples, legal and environmental and health organizations, and economic and commercial enterprises. In as much as it concerns the bio-diversity of the human species, it affects every individual. It is important that monitoring be unbiased and acknowledge the broad spectrum of interests and expertise relevant to genetic research and its applications. To ensure this, the monitoring committee must reflect human diversity and include people with disabilities and other disadvantaged groups. Its membership should include, but not be limited to, scientists, professional ethicists, and experts in jurisprudence. Prudence will need to be exercised to ensure that commercial interests and scientific hegemony do not predominate.



Conclusion

Genetics offers great potential to treat and prevent illness and to promote health and well-being; but there is a danger: genetics could be used to undermine the human rights of people with disabilities, endangering their very existence. A number of fundamental issues emerge in efforts to ensure that genetics is applied in ways that promote health, well-being and human rights.

A propensity to reductionism, reducing concepts to their simplest forms, is one area of concern. The reductionist tendency to view health as simply a biomedical matter, without consideration of the social, environmental and economic elements is a serious risk. So, too, is the process of geneticization, that is, of viewing human diversity and disability as simply a product of DNA codes. Such mind sets lead to notions of perfecting humans by eliminating differences. Science itself is more than objective experimentation. Many complex factors contribute to the way science is perceived and used, as science occurs within the social, cultural and ideological contexts of scientists and society.

Human diversity is a natural characteristic of humankind and is necessary for human survival. Diversity arises out of genetic as well as social, cultural and environmental causes. There is a danger that genetics will lead to a narrowing of social definitions of normality, excluding people with disabilities and other marginalized groups and that this, in turn, will lead to new forms of intolerance and discrimination. More generally, there is a risk that attempts to restrict the diversity of the human genome per se into future generations, will lessen the ability of humanity to adapt and survive.

Eugenics, a term coined in the late 1800s, is based on interpretations of Darwinian concepts of natural selection. The popularity of the eugenics movements that placed value judgements on what kinds of people were desirable, and that

attempted to implement those judgements, culminated in the Holocaust.

Although the world was shocked by the extreme measures applied by the Nazis, eugenic thinking continues to underlie some applications of genetics, and policies exist in some countries that aim to prevent certain types of people from existing. As much as people are generally horrified by the history of eugenics, its principles underlie many medical decisions and policies in countries worldwide.

Science is sometimes viewed as beneficial by nature, and technological advance is equated with social progress. However, scientific research can be used in ways that benefit or harm. When informed by reductionist and eugenic approaches to health, human diversity and disability, the result may be discriminatory and contrary to human rights. There are different kinds of benefit, from economic, to professional, to improve-ments in social well-being and health. Moreover, what benefits one party may harm another. It is therefore important that science be informed and directed by a respect for human diversity, social equality and human rights. Technologies and their applications ought to be evaluated for both a variety of benefits and possible social risks.

Genetic research and technologies raise new questions and require new decisions, from the international political level to the personal lives of individuals. Health and reproductive technologies offer individuals both positive choices and new burdens. In some cases, these choices are restricted by social, legal or economic pressures, or decision-making rights are denied in the individual's 'best interest.' If genetics is to promote health and well-being, people need to be enabled to make free and informed decisions, with the necessary support. More broadly, the direction and application of scientific research depend on the political and ideological bent of governments, corporations, the public and the scientific community. Decisions regarding genetic research are influenced by scientific curiosity, social attitudes about health and disability, and economic considerations. People with disabilities and other marginalized groups need to have the right, within the context of a dialogue, to have a voice in the process of making decisions about genetics, since they are most likely to be adversely affected by such decisions.

Appendix A: Notes for Panel Presentation

TO BE OR NOT TO BE

by Catherine Frazee
The Roeher Institute, Canada

The late Isaiah Berlin, a renowned British philosopher, loved ideas. He understood that ideas are important — ideas matter. He said, "When ideas are neglected by those who ought to attend to them...they often acquire...an irresistible power over multitudes of men that may grow too violent to be affected by rational criticism." He understood that an idea that sounds good is potentially the most dangerous thing in the world.

Ideas matter. In a certain sense, ideas are matter — in other words, they shape and form matter. The printing press, the telephone, the airplane, even the lowly wheel — an object near and dear to my heart! — all began as nothing more than thoughts, notions floating through someone's head — but they now shape our material world so profoundly that members of the younger generation simply can't imagine what the world must have been like before...before electricity, before cars, before zippers, before the computer, etc.

Ideas are important. And they shape more than just the material world. They also shape and form our social world. Democracy is an idea. Hierarchy is nothing more than an idea. Who has power and authority? Who has money? Who has the right to make a decision whose effects will be borne by others? All of these social phenomena are relations that we think of as realities — and yet they are all rooted in thoughts, in ideas.

These ideas that form our social world were the ideas that Isaiah Berlin spent a good deal of his life thinking about. Everyone knows that bombs are dangerous, but the real danger does not lie in the mind that thinks up the idea 'bomb.' The danger lies in the minds of others who design, build, launch and eventually explode the bomb. This is what Berlin was talking about. This is the potentially deadly and catastrophic power of an idea that is neglected by people who ought to attend to it. This is the danger of an idea untempered by human empathy.

As disabled people, we have a unique point of view on empathy. We know that what powerful people think of as empathy often winds up in a judgment that says our lives are too horrible to live and therefore we should be dead. They offer to end our lives to save us from our pain. They tell our mothers that we should not be treated for medical conditions because we will only grow up to have a poor quality of life. They advise our mothers before we are even born, that we should be aborted just in case our disability is too painful or too unpleasant.

They may really think that they have our best interests at heart. But we know better. We know that they are operating out of a mentality which has been shaped and formed by an idea. It is a very old idea — one that has been with the human race for a very, very long time. It is the idea that, if the powerful people could only gain control of all the others, they could create a perfect world. In this perfect world, there would be no disability, there would be no pain or suffering. To quote Berlin (1958), "If one really believes that such a solution is possible, then surely no cost would be too high.... To make such an omelette, there is surely no limit to the number of eggs that should be broken."

The powerful people want to decide for us the answers to questions such as: What is a disability? Whose should live and who should die? Whose life is worthwhile, valuable to society? For some, the answer to these questions lies in the combinations of characteristics scientists are now learning to see in our strands of DNA. Those of us whose genetic make-up differs from their notion of 'perfection' become the eggs which should be broken in pursuit of the perfect omelette, a social Utopia.

These are the ideas that spawned the infamous eugenics movement of the early 20th century. Because the actual science of genetics was in its infancy at that time, they implemented their plans to achieve social control through preventive measures — that is, the surgical sterilization of people deemed to be unfit for parenthood. People with intellectual disabilities were their primary target, but some, perhaps more honest, went further and advocated the sterilization of all people they disliked or mistrusted: people with a range of physical disabilities such as epilepsy, tuberculosis and leprosy, people of other races, poor

people. This was hate disguised as science. The horrific abuse perpetrated by the Nazi regime (and there is surely no need to remind this audience of these atrocities) supposedly turned the world away from eugenics forever.

However, the eugenic idea didn't simply go away. It merely went underground. It is back with us today. The gigantic Human Genome mapping project has been described as science seeking greater understanding of our world. However, we cannot afford to be naive. The Genome project, and genetic research in general, provides fertile ground for the renewed sprouting of the old seeds — the seeds of the deadly eugenics idea.

Potential benefits? Perhaps. Enormous risks? Absolutely.

It is because of the risks of this research that we must protest. Loudly, visibly, clearly. It is so very important, for example, that self-advocates from around the world last week voted to condemn "research and action that aim to remove us from the human race." Protest brings us together. It focuses our energies and helps us achieve solidarity. It educates us so that we can educate others.

Of course, protest alone will not in and of itself stop anything from which powerful people stand to benefit. Eugenics is, above all, a seductive system whereby people who are already in positions of great power express their superiority over the rest of us. Scientific knowledge in general — and genetic science is no exception — claims to be based in a 'value-free' method of detached observation of reality. But we know very well that this is a myth. What scientists study, the questions they ask and the answers they arrive at are all drenched in a value-loaded bath. Research must be funded and if it is not funded, it does not get done.

Knowing this, then, I would like to propose a general strategy for our continuing protest:

In the battle of ideas, the best weapon is an even better idea. Human rights is a far better idea than the idea of perfecting the human race. Human rights thinking maintains that each and every person — regardless of race, sex, religion, ability, sexual preference and so on — is valuable in and of him- or herself.

To build the vision of a human rights-based culture — a culture in which all people are respected, have access to

opportunities and the freedom to pursue our diverse talents, goals and dreams — we need to nourish the idea. We need to promote the idea, first to ourselves, then to others.

I believe that, as a start, we need to understand clearly that our commitment to inclusion does not mean that we accept or seek to be accepted into a mainstream definition of 'normal' — a definition that will always exclude us. This understanding involves actually distancing ourselves from the values of the mainstream and engaging in some deeply creative thinking about our own values. It starts when we value our own selves, our own being and becoming, our own relationships with disabled peers even more highly than we value our economic security and our ability to 'pass' in the so-called normal world. It starts when we call what we do and what we care about most, our 'essential values' — including the unique, often hidden qualities inherent in our disabilities. It starts when we persist in doing and caring in our own way despite lack of recognition, lack of respect and lack of financial support. It starts when we take control of the organizations that claim to represent our interests, but routinely fail to consult with us. It starts when we live fully, daring to express our freedom and our passion despite outward conditions of confinement or oppression.

This is the real power contained within diversity — a concept that is the direct outcome of a human-rights-based approach. And this great power comes to us through our own transformation — our efforts to uproot all those eugenic 'weeds' lurking within our own psyches. I'm talking about a cultural revolution among disabled people and our allies and supporters — a revolution devoted to the development of our pride, our self-respect, our strengths and our commitment to true community — the community of people with disabilities.

Our strategy to promote the human rights idea is similar to what feminists have called consciousness-raising. In the 1960s, in North America at least, women started to get together in small groups to try to understand why, despite having attained an education and achieved the socially valued milestones of success such as a home, marriage and children, we felt so isolated from each other, so dissatisfied and so frustrated. We struggled and

talked together, often blaming something called 'Patriarchy' for our woes, until gradually we began to realize that the seeds of women's oppression are everywhere, not just 'out there' in the constructed social world, not just in the minds and fists of men, but much more dangerously, planted within our own female psyches, our own socialized attitudes and fairy-tale expectations. Just the way that our genes carry and determine the colour of our eyes or skin, our minds unconsciously 'carry' the ideas that sustain oppression — both our own oppression and the oppressions borne by others. And while we cannot change our genes, we can and must change our minds by exposing the roots of those toxic ideas to the hot light of consciousness.

Eugenics is a lot like patriarchy. Eugenics, as an idea, is not a laboratory phenomenon, something owned and controlled by a group of 'mad scientists.' Remember that genetic scientists are not necessarily eugenically minded. Just like the majority of men within patriarchy, they're just living their lives, doing what they, as diverse, scientifically minded people do. They, the scientists in their laboratories, are not the enemy, per se. What is dangerous is allowing to remain unconscious, unexamined, the idea that anyone can legitimately use knowledge and power to control the actions, living conditions and even the very existence of other people.

Our idea of a human-rights-based culture is in its infancy. But unlike the eugenic idea, this new idea is one with no victims. If our idea prevails, some powerful people may become a little bit less powerful but no one will be harmed by this loss of power. As disabled people overcome the shame, guilt and fear that makes us vulnerable to the misuse of genetic science, the rest of society will grow. Scientists will learn to use their power — their knowledge, training, intelligence and access to economic resources — to make our lives longer, healthier, richer and more full of opportunity. This will be possible if they learn to let us, and only us, take the lead in deciding just how science and technology and the ideas behind them should be applied to our lives.

DON'T PREVENT US, INCLUDE US

by Robert Martin
Self-Advocate, Australia

The genetic make-up, which we are born with, decides the physical characteristics that we have when we grow up. Our genes come from both our parents and no two people are born with the same genes. It is our genes that make us the unique persons we are.

The human genome is our unique genes that decides much about the types of persons we become. It decides our hair colour, the colour of our skin, our height, and many of our other physical characteristics, unless science or the beauticians intervene. Many scientists and educators also say that it is a major factor in deciding our personality and intelligence.

We need to understand the human genome and disability. My understanding is that there are many ways we can develop a disability. First we may inherit our disability from one or both of our parents. This happens at the time of conception, well before we are born. Our disability may be apparent when we are born but also may not show up until much later in our lives.

Second, we may get our disability because of disease. After conception we become what is known as a fetus and begin to grow into a baby. If our mother becomes ill, for example with some types of measles, this illness can be passed onto us and we develop a disability.

Third, we may be injured by an accident before we are born and this can give us a disability.

The number four possibility is that certain drugs are taken by our mothers while they are pregnant then this can give us a disability. If our mothers have a poor diet or is exposed to chemicals while pregnant then we may also develop a disability. The disability may either be apparent at birth or later in our lives.

In the past many babies were injured as they were born. I was one of those and my disability is a result of a doctor not taking enough care. As we grow from being a baby, to becoming a child and then an adult, we may have an accident or illness that gives us a disability. Pollution and toxic wastes in our environment may give us an intellectual disability.

We can see that there are many reasons why we may have an intellectual disability. It is not the same for any two people as we each are unique. It is really important that we understand that people can develop an intellectual disability in many ways. Only some inherit their disability from the genes that come from their parents.

In the past some scientists have tried to breed only what they believed were superior people. Research done in the 1920s led Hitler to misusing the information to justify killing millions of people, including those with an intellectual disability. This research is called eugenics and leads people with a disability to being devalued, as they are not seen to be perfect.

Scientists can change the characteristics of vegetables and crops. They can make them grow faster, alter their shape, change their colour and their genetic makeup so they become resistant to disease. They can change the shape of animals, make them grow faster and change their personality. This can be done by selective breeding, which only allows the preferred types of animals or plants to reproduce.

Now the scientists have found new ways to make these changes by either altering the genetic make-up of animals or to clone from an existing animal so we get the characteristics we want. Remember Dolly, the sheep.

Some scientists also believe that we can improve people by altering their genes. Current research will enable this to happen. This will mean that our genes can be altered at conception to make us 'perfect' people. We may be able to choose hair colour, body shape and the intelligence of children before they are born. Some diseased and disabilities may, in the future, be able to be prevented by altering the genetic make-up of people.

We will be able to change the genetic make-up of people so they no longer catch the common cold. Wouldn't that be great!

We will be able to change people's genetic make-up to reduce their risk of disease. Wouldn't that be great!

Through gene therapy we will be able to change the genetic make-up of people so they won't have a disability. Wouldn't that be great!

REALLY?

What does that say about my value as the unique person I am?

A very important principle for mankind is the biological diversity of humanity. This principle accepts that people are of the same value regardless of their biological make-up or genes. This means that those of us with an intellectual disability caused by our biological make-up or genes are of the same value as others.

Another important principle is our inalienable right to life as all others members of the human family. We believe that people with an intellectual disability have the right to be born. Mothers should not be pressured into having testing done on their unborn children to find out if they have a disability and if so, then terminate them.

If we start altering the genes of people to ensure they will be born without a disability then this devalues the life of all other people with a disability. We have the right to be valued for being the persons we are, not because of what others believe we should be.

Our disability is an important part of who we are. It is part of what makes us unique and is an important part of who we become. It is time for all of us to accept disability as being a normal and natural part of life.

It is not our disability that makes us different, it's the thoughts and actions of others. Our live are of no less value because of our disability and we are not a burden on society. We have the right to be proud of who we are, what we are able to achieve and the things we give to others. We have the right to feel proud of ourselves and others should stop trying to take that away from us.

We also need to think about why people with an intellectual disability are devalued in their community. I believe that we are often seen as people who contribute very little to our society or community. We are seen as financial burdens who can never be productive members of the workforce. Western countries place great value on the economic contribution a person makes. They have forgotten our family values and the contribution we can all make to our community.

My greatest fear in this matter is that our society will only see the possibilities for 'improving' the children still to be born. They will not think about the value of people, our diversity or differences and that it's natures way to make us all unique individuals. As people with a disability we will be increasingly

devalued by being seen as not being ideal people and therefore we should be changed.

We are people first, we all have something of value to offer and we and the children with a disability who follow us deserve to be recognized and valued for who they are. As people with a disability, we must be aware of what is taking place in our own countries and be prepared to confront our governments if we are not happy with what's happening. We must ask the organizations that support us to help us in this task. However, we must not be afraid to have our own say and to speak out on behalf of friends who are unable to speak for themselves.

I will leave you with some principles that are important to me.

- We must value every life regardless of abilities or needs.
- We all have the right to be born.
- When all mothers have good diets and access to health education there will be less risk of babies having an intellectual disability due to these reasons.
- We must stop the pollution of our environments so that this stops being a cause of intellectual disability.
- We must not put economic or social pressure on mothers to have their unborn children tested to see if they have a disability.
- We must work along side the scientists so they see our value as real people who have the right to be born.

I am not saying that we don't want to see disability prevented whenever possible. None of us choose to have a disability. However, when science enables us to play around with our genes to fundamentally change the person we will become, then I question the right to do this.

Finally, I will remind you of what I said at the opening on Monday. Our "Together Strong Conference" wants to say that genetic research and testing is being used to strip us of our human

dignity and value. We ask that this Congress condemn research and actions that aim to remove us from the human race.

We say, "Don't prevent us, include us."

WHAT SHOULD WE DO WITH GENETIC INFORMATION?

Dealing with the Dilemmas of Genetic Information

by Dr. Herman P. Meininger, Willem van den Bergh Chair
Vrije Universiteit Amsterdam, The Netherlands

Much has been published about the social consequences of increasing genetic information and the possible applications of this knowledge. These developments continue to cause commotion, often for good reason. In this presentation, however, I do not focus on the social consequences of genetics. My approach to the question, "What should we do with genetic information?" explores the perspective of parents and parents-to-be. These individuals must deal with genetic information that influences, or could have influenced their decisions about having children, or not giving birth to certain children. The experience of parents who have children with intellectual disabilities is a good starting-point in mapping the moral dilemmas inherent in such decisions. So again, let's listen to the story of a parent of a child with intellectual disabilities.

An experience

The story is about a mother. She enthusiastically tells me about her 23-year-old daughter Susan who has Down syndrome. She speaks with love about her child. She proudly tells how her daughter has found a good, rewarding job. She explains how bewildered she was when she heard her daughter's diagnosis. She describes fighting a seemingly endless series of difficulties and set-backs as Susan grew up. She is moved as she tells me the way her daughter has always bound the family together, and continues to play that role. She tells how, above all, the adversities she faced have changed her. She has learned to accept life as it is from day to day. She has learned to value the many small things in life that most people pass over. Through advocating for her child, she has learned to put herself in the position of others. "And yet," says this mother, "if 25 years ago I had access to the genetic tests that exist today, I might have used them. I might have chosen not to bear this child."

Two ways of looking

Does not that story sound strange, even contradictory? What does this mother actually tell us? Does she say that she does not love Susan? No! Does she say that Susan should not be here? No! Does she say that life with Susan has not been worthwhile? No! So what is it she is telling us?

In my view, Susan's mother shows us we can perceive ourselves in different ways. Looking at ourselves 'from within,' most of us would not want to change places with anyone else, despite whatever adversity and pain is in our life. If, however, we look at our life 'from the outside,' in comparison to other people's lives or to the socially dominant ideals of being human, we may then find many things that we would like to change. Susan's mother cannot change things regarding her daughter. Her mission is to reconcile two types of judgment — the judgment 'from within' and the judgment 'from the outside.' By her description of the enrichment she experiences in sharing her life with Susan, it seems that she has made such a reconciliation.

Susan's mother does not deny the difficulties of life with a child with a disability. Nor does she deny that she views herself 'from the outside' and is sensitive to the social ideals of being human, of perfection and of happiness. But at the same time she looks at herself 'from within' and testifies how, by sharing her life with Susan, she has become a better person. She has learned to see her child as a gift, rather than as a problem. She does not consider this to be heroism, but a simple choice to focus on the best interest of her child instead of solely her own feelings. This does not imply that she can tell parents-to-be what to do should they, or their unborn child, be diagnosed with a genetic 'deviation' or as a carrier of such a condition. What she tells us is that the genetic make-up of one's self or one's child is not relevant to the value of either the person or the experience of parenthood. In other words, she teaches us that genetic information has only a very limited meaning in discerning who somebody really is, to herself or to others.

Relativity

The view that genetic information is relative is rare nowadays. This is true both in terms of those who hail the developments in

genetic research and its applications, and by those who firmly protest these developments. For instance, the ethical discussion that views genetics primarily as positive is clouded by the fact that more weight is given to what geneticists say than to the perspectives of persons with intellectual disabilities and their parents. Geneticists promise to use their knowledge and technology to prevent — not cure — suffering associated with living with an intellectual disability. Disease and disability are seen as barriers to free will and free choice — typically valued as the highest capacities of human beings. For this reason, there is pressure to strip away the suffering caused by disease and disability. This notion is the springboard motivating all clinical-genetic research and technology. Many ethicists see it as their task to make sure that the legitimate striving to prevent suffering does not violate social justice and individual autonomy. However, ethicists rarely ask why or how life with an intellectual disability is equated with 'suffering'. If disability is not synonymous with suffering, then why should we prevent life with disabilities?

Suffering

Who suffers and from what? For the most part, persons with intellectual disabilities do not suffer from their disabilities per se. More often they suffer from the pain of discrimination inflicted on them by other people's perceptions of their limited capacities. The reality that people have different capacities, however, should be a challenge to change society so that persons with intellectual disabilities are enabled to participate fully and equally in the life of the community. If persons with intellectual disabilities do indeed suffer as a consequence of their disabilities, in most cases the cause of their suffering does not have a genetic but rather a social character. As we know, social problems cannot be eliminated by way of genetics.

Once again: Who suffers and from what? It is probable that many parents of children with disabilities suffer when they discover that their child is different from most other children. But it is not their child that causes their suffering. They suffer because, like most of us, they have learned that there is only one way to live a good life and enjoy meaningful parenthood — that is, when

parents are healthy and successful and children are perfect and whole. There is pressure for every human being to strive to meet our societal ideals of being human, including the experience of a smooth and progressive development of physical vitality, of mental health and of intellectual brightness. When this is not the case, people are diagnosed as falling below the statistical limits of 'normality,' in whatever way normality is defined. Perhaps parents of disabled children suffer mostly a condition we all share — limitations in our self-images and world views. Susan's mother claims a transformation of that self-image and that world view was necessary for her. Without such a transformation she would not have been able to truly share her life with her daughter.

The possession and application of genetic information does not offer a criticism of our self-images and world views. These are held as self-evident. Superficially, genetic information and our beliefs about humans seem a perfect match. However, on closer look, it is clear that if the dominant self-images and the dominant world views in our societies (and in our hearts) become the measure for applying genetic information, then we could find ourselves caught in a eugenic dream of the re-creation of the human race.

Criticising a self-evident ideal

Persons with intellectual disabilities and their parents challenge us to criticise dominant ideals about being human. They strip away the illusions that characterise these ideals. They teach us that life necessarily includes vulnerability, uncertainties and difficulties. They teach us that life is lived fully only as we struggle to come to terms with the vulnerability, uncertainties and difficulties. Only then life finds its real depth, meaning and worth.

Ethicists, looking for responsible ways of dealing with genetic knowledge and technology, should not be merely concerned with designing protocols, regulations and laws. This work is important, but it is not enough. If we do not challenge our ideals about humanity, we run the risk of accepting, without criticism, the preventive aims of genetic technology, despite our protocols, regulations and laws. We would, without any criticism, repeat the geneticist's axiom that all disabilities with a genetic cause must be

prevented. We would neglect the more fundamental question — should we really try to prevent life with disabilities? Isn't the urge to prevent disabilities based on the presupposition that many problems are caused by the presence of persons with disabilities, for themselves and for other persons involved? Does that not contradict the experiences of many parents (and others) that the presence of persons with disabilities in their lives is a source of meaning? Does it not contradict the experience of many persons with intellectual disabilities themselves, who value their life — including its vulnerability and difficulties — and see their lives as meaningful and worthy?

Conclusion

As a starting point for our discussion this afternoon I conclude with three short theses:

- Preventing disabilities by applying genetic technology is not generally and self-evidently good.
- How we deal with genetic information depends primarily on our own views about the value and meaning of our lives as individuals and as a community.
- How we think about the value and meaning of our life is not static. It can be transformed by significant experiences and choices.

HOW CAN WE HELP FAMILIES SOLVE THE DILEMMAS OF GENETIC INFORMATION

by Mary MacDonagh
FENDIM, Argentina

After we listened to the important dissertations of experts in genetics and bioethics as well as to the experience shared by a mother, my contribution will be a simple one. I will share with you my point of view as an educator and as a person who participates in the parents association movement in Argentina.

In this respect, I bring with me the testimony of mothers of children with severe disabilities. I must also add that I was deeply impressed by the discussions that took place during the "Together Strong" Conference, when this issue was discussed by self-advocates from all over the world.

In order to be able to accomplish the delicate task of participating in this panel, where I replace the President of FENDIM, Mrs. Alicia F. de Sacchi, I asked for the help of three mothers with whom I work trying to help their children with multiple and severe disabilities. I hereby thank Angelica, Hebe and Mabel for having accepted to speak at length about this issue which is not easily accepted in our culture since it stirs many intimate thoughts and can be very disturbing. I thank these three women for agreeing to open their hearts to you.

Together, we reviewed the documents on bioethics of Inclusion International. Our conversation was mainly about abortion and all three agree that they would not accept it. Angelica, for example, considers that it would be the same thing as killing her child, whatever his or her age may be, for the simple reason that he or she would be left with a disability as a result of an accident.

Mabel said that we must take into account the living conditions of every family, as well as the lack of social or economic resources and stability within the family, etc. According to her, we should not judge other families for the decisions they make.

In order to make her position very clear, Hebe sends us a paragraph she wrote. But before I read it to you, I must explain that she has a Ph.D. in Biology and works on an international project on congenital diseases (Study on Congenital

Malformations done in collaboration by countries of Latin America):

" The birth and development of my daughter, Clara, made me think about abortion and take a stand in this matter. I suppose that, before she was born, I wouldn't have considered it so carefully.

The main issue is whether we agree with abortion or not. Of course I cannot judge somebody else's decision. Each of us should decide depending on the circumstances. Nevertheless, I could not do it. At the same time, I am totally against selective abortion.

I am aware of the issues the terms used in the first draft of the Universal Declaration on the Human Genome and Human Rights raise, but I also think that the benefits the study and understanding of the human genome can bring are still incalculable. To know the causes of various disorders or defects could help us develop preventive measures as well as new treatments.

The prejudice against the wrong use of scientific knowledge does not depend on the scientific attitude itself and must be avoided through the development of adequate legislation."

Signed: Hebe Campaña de Goitia

My three friends discussed at great length the significance for their families of having a son or a daughter with a disability. All of them said that their family life has changed. Since it is difficult to go out and take a child with a disability with you, the families have adapted to a rhythm different from that of other families, for example, the couple goes out during the week because on Sundays they must stay at home, etc. My three friends and their husbands, as well as their other children, have accepted this change, although it was not easy; but they are aware that other families couldn't do it, and they can understand it.

They are preoccupied by the superficiality with which some obstetricians ask their patients to undergo special tests as if they were routine tests. They do not explain that such tests could bring up an ethical dilemma, in case the result shows anomalies of the fetus.

Since the three of them are leaders of parents associations, they know many families who find support in the services offered by the associations. But, at the same time, they know families who live far from urban areas and feel abandoned since they can find neither support nor services. Although they do not consider this a very important fact, they believe that families feel that their fears are eased if they have an organization to turn to when they need help and support.

The way in which parents are informed about their children's difficulties can be traumatic. Every year, the Department of Pediatrics of the Faculty of Medicine invites Angelica to speak about her experience as a mother of a girl with disabilities. She speaks in front of students who are about to become doctors. For the great majority of them, this is the first time they hear about disability from a human and social point of view. Together with Associate Professor Ricardo Berridi, Ph.D., Angelica implemented a questionnaire meant to show what medical students know about disability. The results of the survey were published in the magazine "TODOS VALEN" of FENDIM and show that their knowledge of this matter is negligible. (As one of the self-advocates put it in the Conference "Together Strong": "They know absolutely nothing about us.") As a result of this survey, as of this year, the Faculty offers a post-graduate course which involves professionals as well as parents. At the same time, a change in the curriculum of the Medical school is being prepared.

If we apply this perspective to the practical issues raised by bioethics, it becomes easy to understand that the great majority of the professionals who treat mothers-to-be have little or no information on disability and have not been prepared to give adequate advice to pregnant women or to couples if genetic problems are identified. These professionals have very little medical information on the causes of disability, are not aware of the personal and social development potential of people with disabilities, give bad advice or let the families decide by themselves — alone and facing terrible doubt.

Let us imagine a couple faced with the news that their unborn child has or may have disabilities. They are confronted with their personal dilemmas. In cases like this, tests performed because of

the legitimate right to know bring about an immediate, personal and tragic reality.

This other 'Titanic', the ambitious project of 'charting' the human genome collides with the conscience of those who are deeply affected and shaken by the prospect. We are not against building new Titanics; but there are icebergs. We are the icebergs and we are vulnerable to technical progress that would have been unthinkable until a short while ago. Parents such as my three friends bear within them recollections and feelings: the love they felt for their unborn child, hopeful anticipation for a new life, images about what he or she would look like. The idea society has about people with disabilities is very important. If the community accepts and includes them, if they feel relieved and supported, things are easier. But if there is prejudice and discrimination, their life will be even harder.

Moral dilemma hurts. On the one hand there is definite, although not always certain, genetic information that indicates that the fetus has disabilities. But in opposition to it comes anticipation and hope for the baby to come. The book *Just Technology?* suggests how couples or pregnant women should be informed in such cases. There are good examples that make us think that the people who organize these meetings must be trained and prepared for this purpose. Their training should include more than the biological aspects: it should also include issues regarding family life, educational, therapeutic and social support, as well as moral and/or religious support necessary for the couple.

For religious people the presence of a priest, confessor, deacon, rabbi or nun can be of great help. Nevertheless, we are also aware of situations when priests confessed that during their education they were only told that "disabled people are to be treated separately." What can Inclusion International and national and local associations do to improve this situation? My suggestions are the following:

- Develop documents on the implications of scientific research on personal, family and social life. Such documents would have to be studied by scientific associations and professional organizations, as well as in colleges, universities, seminaries, professional training institutions, etc.

- Make sure that the above mentioned documents are written in plain language so that families, self-advocates, community counsellors, volunteers and grassroots organizations can use them.
- Include theoretical and practical courses in curriculums that would make professionals aware of the dilemmas of families confronted with the results of scientific tests.
- Support the training of counsellors, or spiritual or moral advisors who can provide support to families during such crises and moral dilemmas. Psychologists, psychiatrists, social workers, teachers, priests, nuns and the like receive general training in this respect, but they need to know more on this specific issue.
- Last, but not least: we must continue to promote the inclusion of persons with a disability in their communities. If the general public attitude towards people with a disability improves, families will find it less difficult to accept the news that their son or daughter has or will have a disability.

Every gesture of ours, every look, every smile helps. Let us not forget that we are all responsible.

Appendix B: Principles

1. The Principle of Justice

The principle of justice upholds the rights and equality of individuals and groups. This principle affirms fairness and equality in the allocation of resources, whereby everyone has the right to develop her or his potential and is provided with what is necessary to achieve individual and social well-being. It rejects the ethics of economic efficiency and cost effectiveness, and the principles of beneficence and best interest as the sole basis of government obligation.

The principle of justice is based on the presumption that everyone can claim individual rights, fairness and equality. It differs from the principle of beneficence, which involves the provision of benefit and the balancing of benefit and harm. The sole application of beneficence often results in a paternalistic assumption that a person in authority can make a decision in the best interest of another person. Traditional medical ethics and legal systems in liberal democracies have predominantly been based on this notion of beneficence. However, beneficence does not entitle an individual to make a claim for rights. Because the principle of justice allows claims for individual rights and is based on fairness and equality, it involves a much broader and healthier basis for ethical decision-making. One way to determine whether the application of a genetic or reproductive technology incorporates the principle of justice would be to ask the degree to which paternalism is a part of the decision.

Beneficence and paternalism, rather than justice, are at play when disability is accepted as a specific criterion for abortion. Within this framework, prenatal diagnosis followed by the selective abortion of a fetus with a disability is argued to be an act that benefits the fetus. In this view, it is predicted that the fetus will have a poor quality of life, the parents will be burdened by raising a disabled child, and private and public resources will be overburdened in providing supports for a child with a disability.

The application of the principle of justice, on the other hand, starts with a presumption that the right of people with disabilities to be part of society is equal to that of people who do not have disabilities. This principle does not legitimize a paternalistic

decision by a person in a position of authority (such as a doctor) about the continuation of a pregnancy based on the evaluation that such an act would benefit the fetus or its family. Basing a decision to abort on the high costs of providing supports for a person with a disability would not be consistent with the principle of justice. On the contrary, if the principle of justice prevails, all persons have the same right to the support they need to reach their potential and to experience well-being.

The principle of justice, equality and fairness of treatment, means people with disabilities, regardless of the severity of their impairment, have the right to needed medical treatment that would be made available to others. The principle of justice can be applied to the practice of withholding treatment. In some countries, legislation has been proposed that would sanction the withholding of medical treatment from certain groups. Reports from a number of countries suggest that withholding treatment from disabled newborns is commonly practised. It is often justified by assumptions based on paternalism and cost effectiveness. These assumptions include arguments such as mercy killing relieves suffering and is in the best interest of a child with a disability; the lives of people with disabilities are not worth living; medical or financial resources are limited; and the interests of others, such as the distress of families, should take precedence. Once again, the principle of justice leads us to ask: Who has the right to decide which lives are worth living and whether it is indeed a kindness to kill? There can be no compromise in the view that the rights of the child must be of paramount consideration in any decision-making.

Sterilization is another medical procedure influenced by the application of the principle of justice. Several Canadian provinces and American states have a history of legislation that enabled sterilization without the consent of individuals in targeted groups such as people with disabilities. Such practices, justified on the basis of paternalism and beneficence, are in tension with the principle of justice because they deny rights to people with disabilities that are given to others. These include rights to bear children and to have access to supports to raise children.

2. The Principle of Non-Discrimination

The principle of non-discrimination is founded on the belief that everybody has the right to live, to medical treatment, and to be accepted without discrimination based on the existence or expectation of a mental or physical disability.

Under a principle of non-discrimination, people with disabilities have the same right to live, to have access to medical treatment and to be accepted without discrimination based on disability. Prenatal diagnosis and selective abortion provide examples of how the principle of non-discrimination would influence the application of medical technology. In some countries women over the age of 35 are routinely advised to undergo amniocentesis or chorionic villus sampling (CVS). The purpose of these prenatal techniques is often to identify disabling conditions in a fetus. Abortion is often recommended as a course of action if a disability is detected. If the principle of non-discrimination were applied, prenatal diagnosis would not be used as a widespread policy to distinguish disabled fetuses from non-disabled fetuses in order to prevent the births of people with disabilities.

Consent to abortion ought not to be a condition for prenatal diagnosis. For example, a woman should not be required to sign a document as a basis for prenatal testing, promising she will abort a fetus if a disability is detected. Abortion laws and practices must not be drafted in ways that discriminate against people with disabilities. In some countries abortion is legal for a limited term within the pregnancy. Laws that extend the time limit for abortion (for example, from three months to six months) based on the detection of a disability would be discriminatory. In general, there should be no moral or professional pressure to abort a fetus because of the evidence of a disability.

The application of the principle of non-discrimination would require that genetic counselling and counselling before and after prenatal diagnosis be provided in a manner that is non-discriminatory and non-directive. Non-discriminatory and non-directive counselling would respect the value of the life of a person independent of the presence of a disability. This type of counselling would provide social information about the lives of people with disabilities, and would involve a multidisciplinary

approach. Legislation can support this principle. For example, health authorities and professionals could be required by law to give parents contact addresses of support organizations, provide non-directive counselling and to make them aware of the quality of living enjoyed by many people with disabilities.

An emphasis on the use of pre-pregnancy genetic counselling, rather than prenatal diagnosis, is in keeping with the principle of non-discrimination. Pre-pregnancy counselling is a form of family planning. It is less selective and more supportive of diversity. There are suggestions that, in some countries, there is a trend away from pre-pregnancy counselling because the sophistication of prenatal diagnosis makes it easy to detect a handicap after fertilization in time for safe abortion. Although the International League acknowledges the individual choices people make concerning prenatal diagnosis, this procedure ought not to be used as an instrument of eugenic population policy. Women who decide to continue pregnancy after the prenatal diagnosis of a fetus with a disability should not face discrimination for their choice.

Genetic screening and predictive medicine should also be critically evaluated from the perspective of non-discrimination. These technologies have the potential to result in new forms of discrimination against people who are predisposed to develop genetic conditions. This could affect their access to employment or health insurance. The application of the principle of non-discrimination would require that everyone have equal access to employment and health coverage, regardless of disability or any other difference.

3. The Principle of Diversity

The principle of diversity refers to diversity in the population with regard to gender, race, religion, functional capacity, sexual orientation, and so on. Diversity implies not looking for better people, but trying to make a better world to live in. Technologies such as prenatal diagnosis, gene probes, and gene therapy should not be used to rid the world of anyone who does not fit societies' standards of normality or perfection.

The principle of diversity respects the differences of people. Technology, therefore, must be used to enhance life and not to

reduce diversity. Any attempt to use genetic and reproductive developments as tools to reduce human diversity or to select the qualities desired in a population would be in conflict with the principle of diversity. Similarly, any developments that would negatively affect public attitudes about disability and other forms of diversity would be in conflict with this principle. For example, the principle of diversity can be applied to the use of in vitro fertilization and to genetic mapping. From this perspective, there is a risk that this technology could be used to screen embryos for disabilities or differences, selectively implanting those with the qualities deemed desirable. Using the principle of diversity as an ethical measure would protect against the use of technologies such as in vitro fertilization, prenatal diagnosis, gene probes and gene therapy to rid the world of individuals who do not conform to societal standards of normality or perfection.

Technology such as prenatal diagnosis and the practice of selectively aborting fetuses with disabilities may also be used as a means to reduce diversity. The assumptions that some human qualities are better than others, and some fetuses are of better quality than others, are not supportive of diversity. If disability is inevitably associated with elimination, then public attitudes toward, and supports for, people with disabilities may decline.

Technology does have the potential to improve the lives of people with disabilities and the world in which we live. The use of the principle of diversity as an ethical measure would ensure that genetic research would not have a disproportionately negative impact on people because of their disabilities.

4. The Principle of Autonomy and Informed Decision-Making
Every person has the right to receive or refuse medical treatment on the basis of a free and informed decision. If people are of the age to be empowered to make their own decisions, they are entitled to be informed of the nature of the treatment and the consequences (both benefit and risk) of the treatment, of alternative treatments, and of the right to refuse treatment. When a fetus has been diagnosed as having a disability, women (and families) have the right to full information including alternatives to abortion, a positive life perspective of people with

disabilities and knowledge and assurance that they will have access to adequate supports and services should they choose to proceed with the pregnancy.

The principle of autonomy and informed decision-making would ensure that people have the right to choose, or to refuse without undue pressure, the use of genetic and reproductive technology and treatment. This would be true in the case of a whole range of technological applications, and would help ensure fairness and equality of treatment and non-discrimination.

One of the claims of proponents of genetic and reproductive technology is that these technologies enhance choice and autonomy by providing people with information about their fetus or about their own genetic make up, which provides them with real alternatives. The capacity of people with disabilities to lead a full and rich life must be part of the information people receive. The principle of autonomy would require that choices be fully informed. Unfortunately, at present, the people who make or influence decisions about reproductive technology often have limited information about the lives and abilities of people with disabilities. Autonomy and informed decision-making are supported when the information provided to individuals and families about disability goes beyond a medical diagnosis and addresses people's needs and values.

Medical professionals and counsellors can be further informed about these issues through their own professional educational process and through networking with advocacy and support organizations. The principle of autonomy and informed decision making requires that counselling involve a multidisciplinary approach to help families understand facts and alternatives, and supports them to choose a course of action. It does not include pressure from authorities, experts or the public for prenatal diagnosis, abortion, genome analysis, selective implantation, genetic screening or withholding treatment.

The principle of autonomy and informed decision-making can be applied to the practice of withholding treatment. This principle affirms that all people have the right to receive appropriate treatment on the basis of a free and informed decision to consent to treatment. Decisions regarding appropriate treatment must be

made with the full appreciation of the capacities of people with disabilities. Families of a child with a disability require ongoing support. However, the distress or inconvenience of the family or other individuals cannot be the determining factor in the decision about whether an individual should live or die, within the framework of autonomy. Parents may make choices they later regret if they receive inadequate information or lack appropriate support. Medical and legal professionals often do not have sufficient information about disability to advise families. An advocate with full information about the lives of people with disabilities should play a role to ensure that decisions made are informed ones.

Appendix C:

EXCERPTS FROM THE RESPONSE TO UNESCO'S DRAFT DECLARATION SHOWING INCLUSION INTERNATIONAL'S PROPOSED WORDING

Inclusion International has been reviewing and commenting on drafts of UNESCO's Declaration on the Human Genome and Human Rights since September 1995. Inclusion International applied the principles of justice, non-discrimination, diversity and autonomy and informed decision-making to the drafts. This is an example of some of the changes proposed by Inclusion International to ensure the Declaration would reflect these principles. This chart, excerpted from the Response to Draft of a Universal Declaration on the Human Genome and Human Rights Draft of July 1997, compares the Draft Declaration with Inclusion International's proposed wording.

CAPACITY TO CONSENT

[B. Rights of the Persons Concerned]

UNESCO DRAFT DECLARATION (JULY 1997)	INCLUSION INTERNATIONAL PROPOSED WORDING
Article 4a (new 5a) Research, treatment, or diagnosis affecting an individual's genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits pertaining thereto and in accordance with any other requirement of national law.	*Article 4a (new 5a)* Research, treatment or diagnosis affecting an individual's genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits, *including social risks and benefits*, pertaining thereto and in accordance with any other requirement of national law.
Article 4b (new 5b) In all cases, the prior, free and informed consent of the person concerned shall be obtained. If individuals are not in a position without support to communicate their consent or refusal to participate, their wishes will be conveyed by duly authorized representatives. The decision-making processes involving individuals and their representatives will respect human rights, dignity and freedom.	*Article 4b (new 5b)* In all cases, the prior, free and informed consent of the person concerned shall be obtained. *If the latter is not in a position to consent, consent or authorization shall be obtained in the manner prescribed by law, guided by the person's best interest.*

Article 4e (new 5e) If according to the law a person does not have the capacity to consent, research affecting his or her genome may only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law. Research which does not have an expected direct health benefit may only be undertaken by way of exception, with utmost restraint, exposing the person only to a minimal risk and minimal burden and if the research is intended to contribute to the health benefit of other persons in the same age category or with the same genetic condition, subject to the conditions prescribed by law, and provided such research is compatible with the protection of the individuals human rights.	*Article 4e (new 5e)* If according to the law a person does not have the capacity to consent, research affecting his or her genome may only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law.
Article 5 (new 6) No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.	*Article 5 (new 6)* No one *or group* shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.
Article 6 (new 7) Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions foreseen by law.	*Article 6 (new 7)* Genetic data associated with an identifiable person *or group* and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions foreseen by law.
Article 7 (new 8) Every individual shall have the right, according to International and national law, to just reparation for damage sustained as a direct and determining result of an intervention affecting his or her genome.	*Article 7 (new 8)* Every individual *or discriminated group* shall have the right, according to International and national law, to just reparation for damage sustained as a direct and determining result of an intervention affecting his or her genome.

PROHIBITION OF EUGENIC PRACTICES

[Section E. Solidarity and International Co-operation]

UNESCO Draft Declaration (July 1997)	Inclusion International Proposed Wording
Article 14 (new 17) States should respect and promote the practice of solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disability of a genetic character. They should foster inter alia research on identification, prevention and treatment of genetically based and genetically influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population.	*Article 14 (new 17)* States should respect and promote the practice of solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disability of a genetic character. *To this end*, they should foster research on identification, prevention and treatment of genetically based and genetically influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population. *At the same time, states must strongly reject all eugenic programs as discriminatory and contrary to the safeguarding of personal and common genetic heritage. States must also affirm that biodiversity is inherently desirable and must be protected.*

[Section C. Research on the Human Genome]

Article 8bis (new 11) Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. States and competent international organizations are invited to co-operate in identifying such practices and in determining, nationally or internationally, appropriate measures to be taken to ensure that the principles set out in this Declaration are respected.	*Article 8bis (new 11)* Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. *Gene research and its application that has or could be interpreted to have eugenic purposes or outcomes shall not be permitted.* States and competent international organizations are invited to co-operate in identifying such practices and in determining, nationally or internationally, appropriate measures to be taken to ensure that the principles set out in this Declaration are respected.

MONITORING [Section G. Implementation of the Declaration]

UNESCO Draft Declaration (July 1997)	Inclusion International Proposed Wording
Article 21 (new 24) The International Bioethics Committee of UNESCO should contribute to the dissemination of the principles set out in this Declaration and to further the examination of issues raised by their applications and the evolution of the technologies in question. It should organize appropriate consultations with parties concerned, such as vulnerable groups. It should make recommendations addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular the identification of practices that could be contrary to human dignity, such as germline interventions.	*Article 21 (new 24)* An *International Implementation Committee on the Human Genome and Human Rights of the United Nations, comprised of representative member states, representative experts, representative human rights organizations and representative impacted vulnerable groups*, should contribute to the dissemination of the principles set out in this Declaration and to further the examination of issues raised by their applications and the evolution of the technologies in question. It should organize appropriate consultations with parties concerned, such as vulnerable groups *and other relevant United Nations agencies*. It should make recommendations addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular the identification of practices that could be contrary to human dignity, *human rights and fundamental freedoms* such as germline interventions.
Article 20 (new 23) States shall take appropriate measures to promote, through education, training and information dissemination, respect for the aforementioned principles and to foster their recognition and effective application. States should also encourage exchanges and networks between independent ethics committees, as they are established, to foster full collaboration.	*Article 20 (new 23)* States shall take appropriate measures to promote, through education, training and information dissemination, respect for the aforementioned principles and to foster their recognition and effective application. States should also encourage exchanges and networks between *independent human rights organizations and* independent ethics committees, as they are established, to foster full collaboration. *States should foster and advise on national law that will promote the principles of this Declaration.*

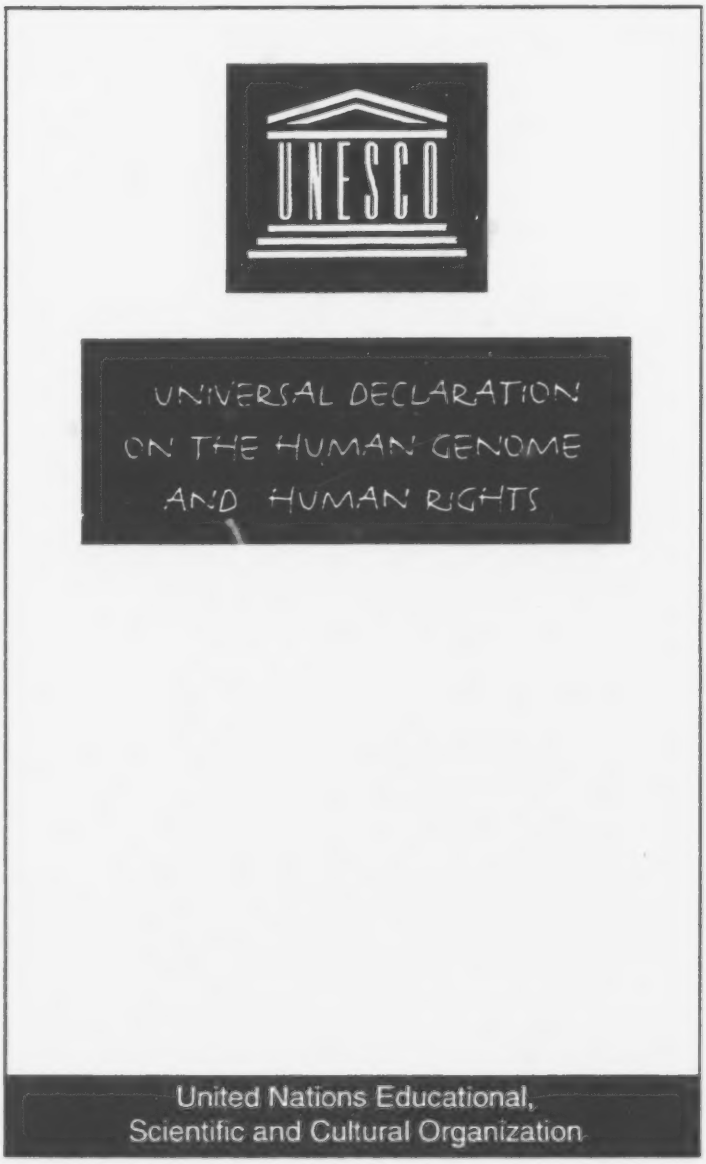
PURPOSE OF RESEARCH TO PROMOTE HEALTH AND WELL-BEING

[Section C. Research on the Human Genome]

UNESCO Draft Declaration (July 1997)	Inclusion International Proposed Wording
Article 9b (new article 12b) Freedom of research, which is necessary to the process of knowledge, is part of the freedom of thought. The applications of research, including those in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole.	*Article 9b (new article 12b)* Freedom of research, which is necessary to the process of knowledge, is part of the freedom of thought. *Research and* the applications of research, including those in biology, genetics and medicine, concerning the human genome *should promote the health and well-being of individuals.*

Appendix D:

UNESCO'S UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS

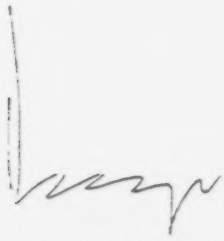


PREFACE

The Universal Declaration on the Human Genome and Human Rights, which was adopted unanimously and by acclamation by the General Conference of UNESCO at its 29th session on 11 November 1997, is the first universal instrument in the field of biology. The uncontested merit of this text resides in the balance it strikes between safeguarding respect for human rights and fundamental freedoms and the need to ensure freedom of research.

Together with the Declaration, UNESCO's General Conference adopted a resolution for its implementation, which commits States to taking appropriate measures to promote the principles set out in the Declaration and encourage their implementation.

The moral commitment entered into by States in adopting the Universal Declaration on the Human Genome and Human Rights is a starting point, the beginning of international awareness of the need for ethical issues to be addressed in science and technology. It is now up to States, through the measures they decide to adopt, to put the Declaration into practice and thus ensure its continued existence.



Federico Mayor

3 December 1997

Universal Declaration on the Human Genome and Human Rights

The General Conference,

Recalling that the Preamble of UNESCO's Constitution refers to 'the democratic principles of the dignity, equality and mutual respect of men', rejects any 'doctrine of the inequality of men and races', stipulates 'that the wide diffusion of culture, and the education of humanity for justice and liberty and peace are indispensable to the dignity of men and constitute a sacred duty which all the nations must fulfil in a spirit of mutual assistance and concern', proclaims that 'peace must be founded upon the intellectual and moral solidarity of mankind', and states that the Organization seeks to advance 'through the educational and scientific and cultural relations of the peoples of the world, the objectives of international peace and of the common welfare of mankind for which the United Nations Organization was established and which its Charter proclaims',

Solemnly recalling its attachment to the universal principles of human rights, affirmed in particular in the Universal Declaration of Human Rights of 10 December 1948 and in the two International United Nations Covenants on Economic, Social and Cultural Rights and on Civil and Political Rights of 16 December 1966, in the United Nations Convention on the Prevention and Punishment of the Crime of Genocide of 9 December 1948, the International United Nations Convention on the Elimination of All Forms of Racial Discrimination of 21 December 1965, the United Nations Declaration on the Rights of Mentally Retarded Persons of 20 December 1971, the United Nations Declaration on the Rights of Disabled Persons of 9 December 1975, the United Nations Convention on the Elimination of All Forms of Discrimination Against Women of 18 December 1979, the United Nations Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power of 29 November 1985, the United Nations Convention on the Rights of the Child of 20 November 1989, the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities of 20 December 1993, the Convention on the Prohibition of the Development, Production and Stockpiling of Bacteriological (Biological) and Toxin Weapons and on their Destruction of 16 December 1971, the UNESCO Convention against Discrimination in Education of 14 December 1960, the UNESCO Declaration of the Principles

of International Cultural Co-operation of 4 November 1966, the UNESCO Recommendation on the Status of Scientific Researchers of 20 November 1974, the UNESCO Declaration on Race and Racial Prejudice of 27 November 1978, the ILO Convention (N°111) concerning Discrimination in Respect of Employment and Occupation of 25 June 1958 and the ILO Convention (N°169) concerning Indigenous and Tribal Peoples in Independent Countries of 27 June 1989,

Bearing in mind, and without prejudice to, the international instruments which could have a bearing on the applications of genetics in the field of intellectual property, *inter alia* the Bern Convention for the Protection of Literary and Artistic Works of 9 September 1886 and the UNESCO Universal Copyright Convention of 6 September 1952, as last revised in Paris on 24 July 1971, the Paris Convention for the Protection of Industrial Property of 20 March 1883, as last revised at Stockholm on 14 July 1967, the Budapest Treaty of the WIPO on International Recognition of the Deposit of Micro-organisms for the Purposes of Patent Procedures of 28 April 1977, and the Trade Related Aspects of Intellectual Property Rights Agreement (TRIPs) annexed to the Agreement establishing the World Trade Organization, which entered into force on 1st January 1995,

Bearing in mind also the United Nations Convention on Biological Diversity of 5 June 1992 and *emphasizing* in that connection that the recognition of the genetic diversity of humanity must not give rise to any interpretation of a social or political nature which could call into question 'the inherent dignity and (...) the equal and inalienable rights of all members of the human family', in accordance with the Preamble to the Universal Declaration of Human Rights,

Recalling 22 C/Resolution 13.1, 23 C/Resolution 13.1, 24 C/Resolution 13.1, 25 C/Resolutions 5.2 and 7.3, 27 C/Resolution 5.15 and 28 C/Resolutions 0.12, 2.1 and 2.2, urging UNESCO to promote and develop ethical studies, and the actions arising out of them, on the consequences of scientific and technological progress in the fields of biology and genetics, within the framework of respect for human rights and fundamental freedoms,

Recognizing that research on the human genome and the resulting applications open up vast prospects for progress in improving the health of individuals and of humankind as a whole, but *emphasizing* that such research should fully respect human dignity, freedom and human rights, as well as the prohibition of all forms of discrimination based on genetic characteristics,

Proclaims the principles that follow and *adopts* the present Declaration.

A. HUMAN DIGNITY AND THE HUMAN GENOME

Article 1

The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.

Article 2

a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.

b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.

Article 3

The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment including the individual's state of health, living conditions, nutrition and education.

Article 4

The human genome in its natural state shall not give rise to financial gains.

B. RIGHTS OF THE PERSONS CONCERNED

Article 5

a) Research, treatment or diagnosis affecting an individual's genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits pertaining thereto and in accordance with any other requirement of national law.

b) In all cases, the prior, free and informed consent of the person concerned shall be obtained. If the latter is not in a position to consent, consent or authorization shall be obtained in the manner prescribed by law, guided by the person's best interest.

c) The right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.

d) In the case of research, protocols shall, in addition, be submitted for prior review in accordance with relevant national and international research standards or guidelines.

e) If according to the law a person does not have the capacity to consent, research affecting his or her genome may only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law. Research which does not have an expected direct health benefit may only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and if the research is intended to contribute to the health benefit of other persons in the same age category or with the same genetic condition, subject to the conditions prescribed by law, and provided such research is compatible with the protection of the individual's human rights.

Article 6

No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

Article 7

Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law.

Article 8

Every individual shall have the right, according to international and national law, to just reparation for any damage sustained as a direct and determining result of an intervention affecting his or her genome.

Article 9

In order to protect human rights and fundamental freedoms, limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights.

C. RESEARCH ON THE HUMAN GENOME

Article 10

No research or research applications concerning the human genome, in particular in the fields of biology, genetics and medicine, should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people.

Article 11

Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. States and competent international organizations are invited to co-operate in identifying such practices and in taking, at national or international level, the measures necessary to ensure that the principles set out in this Declaration are respected.

Article 12

a) Benefits from advances in biology, genetics and medicine, concerning the human genome, shall be made available to all, with due regard for the dignity and human rights of each individual.

b) Freedom of research, which is necessary for the progress of knowledge, is part of freedom of thought. The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole.

D. CONDITIONS FOR THE EXERCISE OF SCIENTIFIC ACTIVITY

Article 13

The responsibilities inherent in the activities of researchers, including meticulousness, caution, intellectual honesty and integrity in carrying out their research as well as in the presentation and utilization of their findings, should be the subject of particular attention in the framework of research on the human genome, because of its ethical and social implications. Public and private science policy-makers also have particular responsibilities in this respect.

Article 14

States should take appropriate measures to foster the intellectual and material conditions favourable to freedom in the conduct of research on the human genome and to consider the ethical, legal, social and economic implications of such research, on the basis of the principles set out in this Declaration.

Article 15

States should take appropriate steps to provide the framework for the free exercise of research on the human genome with due regard for the principles set out in this Declaration, in order to safeguard respect for human rights, fundamental freedoms and human dignity and to protect public health. They should seek to ensure that research results are not used for non-peaceful purposes.

Article 16

States should recognize the value of promoting, at various levels, as appropriate, the establishment of independent, multidisciplinary and pluralist ethics committees to assess the ethical, legal and social issues raised by research on the human genome and its application.

E. SOLIDARITY AND INTERNATIONAL CO-OPERATION

Article 17

States should respect and promote the practice of solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disability of a genetic character. They should foster, *inter alia*, research on the identification, prevention and treatment of genetically-based and genetically-influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population.

Article 18

States should make every effort, with due and appropriate regard for the principles set out in this Declaration, to continue fostering the international dissemination of scientific knowledge concerning the human genome, human diversity and genetic research and, in that regard, to foster scientific and cultural co-operation, particularly between industrialized and developing countries.

Article 19

a) In the framework of international co-operation with developing countries, States should seek to encourage measures enabling:

i) assessment of the risks and benefits pertaining to research on the human genome to be carried out and abuse to be prevented;

ii) the capacity of developing countries to carry out research on human biology and genetics, taking into consideration their specific problems, to be developed and strengthened;

iii) developing countries to benefit from the achievements of scientific and technological research so that their use in favour of economic and social progress can be to the benefit of all;

iv) the free exchange of scientific knowledge and information in the areas of biology, genetics and medicine to be promoted.

b) Relevant international organizations should support and promote the initiatives taken by States for the above-mentioned purposes.

F. PROMOTION OF THE PRINCIPLES SET OUT IN THE DECLARATION

Article 20

States should take appropriate measures to promote the principles set out in the Declaration, through education and relevant means, *inter alia* through the conduct of research and training in interdisciplinary fields and through the promotion of education in bioethics, at all levels, in particular for those responsible for science policies.

Article 21

States should take appropriate measures to encourage other forms of research, training and information dissemination conducive to raising the awareness of society and all of its members of their responsibilities regarding the fundamental issues relating to the defence of human dignity which may be raised by research in biology, in genetics and in medicine, and its applications. They should also undertake to facilitate on this subject an open international discussion, ensuring the free expression of various socio-cultural, religious and philosophical opinions.

G. IMPLEMENTATION OF THE DECLARATION

Article 22

States should make every effort to promote the principles set out in this Declaration and should, by means of all appropriate measures, promote their implementation.

Article 23

States should take appropriate measures to promote, through education, training and information dissemination, respect for the abovementioned principles and to foster their recognition and effective application. States should also encourage exchanges and networks among independent ethics committees, as they are established, to foster full collaboration.

Article 24

The International Bioethics Committee of UNESCO should contribute to the dissemination of the principles set out in this Declaration and to the further examination of issues raised by their applications and by the evolution of the technologies in question. It should organize appropriate consultations with parties concerned, such as vulnerable groups. It should make recommendations, in accordance with UNESCO's statutory procedures, addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular regarding the identification of practices that could be contrary to human dignity, such as germ-line interventions.

Article 25

Nothing in this Declaration may be interpreted as implying for any State, group or person any claim to engage in any activity or to perform any act contrary to human rights and fundamental freedoms, including the principles set out in this Declaration.

Implementation of the Universal Declaration on the Human Genome and Human Rights

The General Conference,

Considering the Universal Declaration on the Human Genome and Human Rights, which was adopted on this eleventh day of November 1997,

Noting that the considerations formulated by the Member States at the time of the adoption of the Universal Declaration are relevant for the follow-up of the Declaration,

1. *Urges* Member States:

   (a) in the light of the provisions of the Universal Declaration on the Human Genome and Human Rights, to take appropriate steps, including where necessary the introduction of legislation or regulations, to promote the principles set forth in the Declaration, and to promote their implementation;

   (b) to keep the Director-General regularly informed of all measures they have taken to implement the principles set forth in the Declaration;

2. *Invites* the Director-General:

   (a) to convene as soon as possible after the 29th session of the General Conference an *ad hoc* working group with balanced geographical representation, comprised of representatives of Member States, with a view to advising him on the constitution and the tasks of the International Bioethics Committee with respect to the Universal Declaration and on the conditions, including the breadth of consultations, under which it will ensure the follow-up to the said Declaration, and to report on this to the Executive Board at its 154th session;

   (b) to take the necessary steps to enable the International Bioethics Committee to ensure the dissemination and follow-up of the Declaration, and promotion of the principles set forth therein;

(c) to prepare for the General Conference a global report on the situation world-wide in the fields relevant to the Declaration, on the basis of information supplied by the Member States and of other demonstrably trustworthy information gathered by whatever methods he may deem appropriate;

(d) to take due account, in the preparation of his global report, of the work of the organizations and agencies of the United Nations system, of other intergovernmental organizations, and of the competent international non-governmental organizations;

(e) to submit his global report to the General Conference, together with whatever general observations and recommendations may be deemed necessary in order to promote the implementation of the Declaration.

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Thanks to advances in genetic research and technology, we now know far more about human genetic make-up. As science progresses, we will soon be able to predict a great deal about our likelihood to have certain characteristics, or to develop various conditions, diseases or disabilities.

These developments in genetics raise many moral and ethical questions about what we value in ourselves as human beings, and how this new information about our genetic structure will affect us as individuals and as a society.

Genome(s) and Justice explores the complicated issues of genetic research and technology and looks at the impact of these developments, particularly with respect to how they may affect people with disabilities.

Four principles are outlined, providing a framework for evaluating genetic research and its applications: The Principle of Justice, The Principle of Non-Discrimination; The Principle of Diversity; The Principle of Autonomy and Informed Decision-Making.

This framework has been applied by The Roeher Institute and Inclusion International to evaluate and recommend changes to UNESCO's "Declaration on the Protection of the Human Genome". *Genome(s) and Justice* is a guide to these issues, and discussion of how they emerged through the evaluation of the UNESCO Declaration.

A follow-up to *Just Technology*, *Genome(s) and Justice* is a timely and informative document in the ongoing dialogue on genetic research and its applications.